

**Interest, Understanding, and Behaviour: Conceptualizations of Sexuality Education  
for Individuals with an Autism Spectrum Disorder  
Using a Socially Inclusive Lens**

Nathalie A. Gougeon

Thesis submitted to the Faculty of Graduate and Postdoctoral Studies in partial fulfilment  
of the requirements for the Ph.D. degree in Education.

Faculty of Education

University of Ottawa

© Nathalie A. Gougeon, Ottawa, Canada, 2013

## **Abstract**

Research shows that there is a gap between interest and experience in the area of sexuality for individuals with autism. Also, although these individuals have unique learning requirements pertaining to their sexuality, there is no consensus on the provision and content of such education. Using a socially inclusive theoretical lens founded on existing models of disability and competence, this bilingual study (a) developed a conceptual framework of sexuality education, as understood by adolescents living in Ontario with a diagnosis of high-functioning autism and their caregivers; (b) used extant texts to support the conceptualization provided by youth and caregivers; and (c) identified personal strengths and barriers, as well as societal supports and barriers that impact sexuality education for these youth. Using a qualitative orientation, this study employed in-depth interviews, surveys, and a literature review to better understand the topic under investigation. Twenty participants from 8 families took part in these interviews, including 9 adolescents and 11 caregivers. Survey and extant textual-analysis data were used to support the findings. Sexuality education content was conceptualized as a combination of facts and sociosexual norms, with emphasis on outcomes. Additionally, safety and pleasure were identified as important content areas, including the historically absent aspect of shared enjoyment. Some content areas were part of a greater discourse of normalization. Sexuality education was seen as a combination of formal and informal activities that are developmentally appropriate, proactive, and take place across various settings and groupings. Caregivers were cited as the primary providers of informal education, whereas schools and other community partners were seen as formal providers of education. Various supports and barriers were identified, some of which were viewed

as both. Themes related to media and technology pervaded all findings. This study provides further emic and etic understanding of the subject with implications for practice, policy, and theory.

*Keywords:* high-functioning autism, Asperger syndrome, sexuality education, social inclusion

## Acknowledgements

I would like to thank the many people who made this thesis possible. Thank you God, this is finally done. Thank you to my family and friends for your unwavering support. In particular, thank you to my husband, Patrick, for being so incredibly patient and supportive throughout this journey: I could not have done this without you. To my daughter, Odette, for being a stellar sleeper even in your first months, thus allowing me time to write. To my parents, Johanna and Pierre, for always believing in me, with a special thanks to my mom for babysitting during those final months of writing and editing. To my parents-in-law, Eileen and Dennis for their gentle encouragement every step of the way. Thank you to the Pipsters for your inspiration and motivation.

Sincere thanks to my committee members, Dr. Cheryll Duquette, Dr. John Lyons, and Dr. Jessica Whitley for your guidance throughout this process. Thank you to Dr. Jacques Forget, external examiner, for your insightful suggestions and contributions at the oral defense. A heartfelt thanks to my thesis supervisor, Dr. Carole Sénéchal, for being a tireless advocate and supporter.

Thank you to Dr. Shana Nichols, for kindly allowing me to use your research tools for this project. Thank you to the Ontario Ministry of Training, Colleges and Universities for its financial support through the Ontario Graduate Scholarship Program. Thank you to Autism Ontario, the Geneva Centre, le regroupement de parents d'adolescents Asperger francophones, the Asperger Society of Ontario, and Autism Speaks. A special thank you to the Children's Hospital of Eastern Ontario (CHEO) for supporting this project. Thank you to Dr. Lise Bisnaire for your guidance and kind words, as well as to Vlatko Dabic, for your insights into education for youth with high-

functioning autism. Finally, thank you to the youth and caregivers who participated in this research project. With gratitude and admiration, I dedicate this thesis to you.

## Table of Contents

<b>Abstract .....</b>	<b>ii</b>
<b>Acknowledgements .....</b>	<b>iv</b>
<b>List of Tables .....</b>	<b>viii</b>
<b>List of Figures .....</b>	<b>ix</b>
<b>CHAPTER 1: INTRODUCTION .....</b>	<b>1</b>
<i>Background and Context .....</i>	<i>2</i>
<i>Problem Statement.....</i>	<i>7</i>
<i>Statement of Purpose and Research Questions.....</i>	<i>8</i>
<i>Research Approach.....</i>	<i>8</i>
<i>The Researcher .....</i>	<i>9</i>
<i>Rationale and Significance .....</i>	<i>11</i>
<i>Definitions of Key Terminology.....</i>	<i>12</i>
<i>Dissertation Overview .....</i>	<i>15</i>
<b>CHAPTER 2: LITERATURE REVIEW .....</b>	<b>17</b>
<i>Introduction .....</i>	<i>17</i>
<i>Definitions of Key Terms .....</i>	<i>17</i>
<i>Research on Sexuality and Autism.....</i>	<i>23</i>
<i>Discussion.....</i>	<i>38</i>
<i>Chapter Summary .....</i>	<i>45</i>
<b>CHAPTER 3: THEORETICAL FRAMEWORK .....</b>	<b>46</b>
<i>Introduction .....</i>	<i>46</i>
<i>Inclusion: Past and Present.....</i>	<i>46</i>
<i>Epistemological Contextualization of Research .....</i>	<i>52</i>
<i>Evolutionary Development of a Socially Inclusive Theoretical Framework .....</i>	<i>54</i>
<i>Sexuality Education in a Framework of Social Inclusion: Current Investigation .....</i>	<i>63</i>
<i>Chapter Summary .....</i>	<i>67</i>
<b>CHAPTER 4: METHODOLOGY .....</b>	<b>68</b>
<i>Introduction .....</i>	<i>68</i>
<i>Research Design .....</i>	<i>68</i>
<i>Participants and Recruitment Strategies .....</i>	<i>72</i>
<i>Data Sources and Data-Collection Instruments .....</i>	<i>76</i>
<i>Ethical Considerations .....</i>	<i>80</i>
<i>Data Collection and Analyses.....</i>	<i>83</i>
<i>Issues of Trustworthiness.....</i>	<i>87</i>
<i>Limitations .....</i>	<i>89</i>
<i>Chapter Summary .....</i>	<i>91</i>
<b>CHAPTER 5: INTERVIEW AND SURVEY FINDINGS .....</b>	<b>93</b>
<i>Introduction .....</i>	<i>93</i>
<i>Research Question 1: What does sexuality education mean for youth with high-functioning autism and their caregivers? .....</i>	<i>100</i>
<i>Research Question 2: How do prior literature, policy, and curricula in this field inform this definition? .....</i>	<i>137</i>
<i>Research Question 3: In the context of sexuality education for youth with high-functioning autism, what are the supports and barriers encountered by these youth and what are their impact(s)? .....</i>	<i>137</i>
<i>Summary.....</i>	<i>174</i>
<i>Chapter Summary .....</i>	<i>180</i>

<b>CHAPTER 6: TEXTUAL FINDINGS AND ANALYSIS .....</b>	<b>181</b>
<i>Introduction .....</i>	<i>181</i>
<i>Research Question 2: .....</i>	<i>187</i>
<b>CHAPTER 7: SYNTHESIS AND CONCLUSION .....</b>	<b>212</b>
<i>Introduction .....</i>	<i>212</i>
<i>Summary of Findings .....</i>	<i>213</i>
<i>Synthesis .....</i>	<i>218</i>
<i>Research Questions 1 &amp; 2 .....</i>	<i>220</i>
<i>Research Question 3 .....</i>	<i>249</i>
<i>Socially Inclusive Theoretical Framework Revisited .....</i>	<i>258</i>
<i>Summary of Final Findings .....</i>	<i>259</i>
<i>Suggestions .....</i>	<i>260</i>
<i>Limitations .....</i>	<i>262</i>
<i>Contributions .....</i>	<i>263</i>
<i>Final Thoughts .....</i>	<i>265</i>
<b>References .....</b>	<b>267</b>
<b>Appendices .....</b>	<b>289</b>
<i>Appendix A: Sexuality and Autism: A Critical Review of Selected Literature Using a Social-Relational Model of Disability .....</i>	<i>291</i>
<i>Appendix B: Summary of Sexuality Studies about Individuals with Autism Detailed in Literature Review .....</i>	<i>325</i>
<i>Appendix C: Visual Representation of Conceptual Framework and Linkages to Research Questions .....</i>	<i>331</i>
<i>Appendix D: Sample Recruitment Poster (English) .....</i>	<i>332</i>
<i>Appendix E: Sample Recruitment Poster (French) .....</i>	<i>333</i>
<i>Appendix F: Introductory Letter (English) .....</i>	<i>334</i>
<i>Appendix G: Introductory Letter (French) .....</i>	<i>335</i>
<i>Appendix H: Consent to Contact Form (English) .....</i>	<i>336</i>
<i>Appendix I: Consent to Contact Form (French) .....</i>	<i>337</i>
<b>Appendix J: Coding Scheme for Research Questions and Table of Specifications .....</b>	<b>338</b>
<b>Appendix K: Caregiver Consent Form and Survey (English) .....</b>	<b>340</b>
<b>Appendix L: Caregiver Consent Form and Survey (French) .....</b>	<b>355</b>
<b>Appendix M: Youth Consent Form and Survey (English) .....</b>	<b>371</b>
<i>Appendix N: Youth Consent Form and Survey (French) .....</i>	<i>382</i>
<i>Appendix O: Caregiver Consent Form and Interview Rubric (English) .....</i>	<i>393</i>
<i>Appendix P: Caregiver Consent Form and Interview Rubric (French) .....</i>	<i>400</i>
<i>Appendix Q: Youth Consent Form and Interview Rubric (English) .....</i>	<i>407</i>
<i>Appendix R: Youth Consent Form and Interview Rubric (French) .....</i>	<i>413</i>
<i>Appendix S: Resource List (English) .....</i>	<i>420</i>
<i>Appendix T: Resource List (French) .....</i>	<i>426</i>
<i>Appendix U: Summary of Dimensions of Sexuality Education Modality .....</i>	<i>433</i>
<i>Appendix V: Summary of Sexuality Education Content .....</i>	<i>437</i>
<i>Appendix W: Summary of Manifestations of Sexuality Education .....</i>	<i>440</i>
<i>Appendix X: Complete and Interim Sexuality Contents of the Revised Ontario Curriculum, Grades 1 to 8: Health and Physical Education .....</i>	<i>441</i>
<i>Appendix Y: Sexuality Contents of the Ontario Curriculum, Grades 9 to 12: Healthy Living &amp; Healthy Growth and Sexuality .....</i>	<i>452</i>
<i>Appendix Z: Key Concepts and Topics of Comprehensive Sexuality Education .....</i>	<i>454</i>
<i>Appendix AA: Visual Representation of Completed Conceptual Framework with Linkages to Research Questions .....</i>	<i>455</i>
<i>Appendix BB: Summary of Complete Findings .....</i>	<i>457</i>

## **List of Tables**

Table 1 Youth Survey Participant Demographic Information .....	74
Table 2 Caregiver Survey Participant Demographic Information .....	75
Table 3 Interview Participant Demographic Information.....	77
Table 4 Summary of Dimensions of Sexuality Education Modality According to Youth and Caregivers .....	101
Table 5 Summary of Dimensions of Sexuality Education Content According to Youth and Caregivers .....	117
Table 6 Summary of Dimensions of the Manifestations of Sexuality Education According to Caregivers .....	132
Table 7 Summary of Individual Strengths Identified by Youth and Caregivers .....	138
Table 8 Summary of External Supports Identified by Youth and Caregivers .....	146
Table 9 Summary of Individual Barriers Identified by Youth and Caregivers.....	155
Table 10 Summary of External Barriers Identified by Youth and Caregivers .....	165
Table 11 Summary of content areas from current Ontario curriculum, Grades 7–12 .....	184

## List of Figures

Figure 1. Adapted COMPASS theoretical framework of competence. ....	56
Figure 2. Adapted social-relational theoretical framework of disability. ....	58
Figure 3. Adapted hybrid socially-inclusive theoretical framework. ....	62
Figure 4. Sexuality Education viewed through hybrid socially inclusive theoretical framework .....	64
Figure 5. Adapted Hybrid Model of Concept Development.....	69
Figure 6. Adapted Hybrid Model of Concept Development.....	70
Figure 7. Updated Adapted Hybrid Model of Concept Development. ....	71
Figure 8. Tentative Hybrid Socially-Inclusive Theoretical Framework of Sexuality Education. ....	219
Figure 9. Revised hybrid theoretical framework of social inclusion. ....	258

## CHAPTER 1: INTRODUCTION

*It's hugely important. That is the biggest thing that I think for him is the whole relationship aspect. And so much of the other stuff is just trivial by comparison.*

(Ronan, caregiver)

*Like we're taught everything that happens in a relationship and it goes on from there, but we're not really taught basically when it's gonna all happen.*

(Jeremiah, youth)

The purpose of this bilingual study was to develop a conceptual framework of sexuality education, defined by youth with high-functioning autism and their caregivers, and informed by the literature. In addition, in this study I sought to identify the personal and societal supports and barriers that facilitate or hinder access to sexuality education for these youth. I also aimed to inform emerging theory, policy, program, and curriculum development in the fields of sexuality education and autism, which could potentially improve social outcomes for individuals with high-functioning autism. Most importantly, however, my goal was to give voice to the often-studied but seldom-heard youth with high-functioning autism on the very personal and important topic of *their* sexuality education. Using a qualitative approach, this study adopted in-depth interview and survey methodologies to seek meaning and understanding of the topic under investigation. Twenty participants from eight families from Ontario participated in in-depth interviews, including nine youth with high-functioning autism and 11 of their caregivers. Survey and extant textual analysis data were used to support or qualify the findings.

This chapter begins with an overview of the background and context outlining the study. Next, I propose the problem statement, the statement of purpose, and the associated research questions. I also briefly touch on the research approach adopted for this study, as well as situate myself in the research context. Finally, this introductory chapter ends with a discussion on the proposed rationale and significance of this investigation, provides some information on key terminology, and offers an overview of the remaining chapters of this dissertation.

## **Background and Context**

When broaching the subject of sexuality education, most stakeholders agree it is a much needed aspect of the overall education provided to individuals with developmental disabilities (e.g., Craft, 1994; Gerouki, 2007; Howard-Barr, Rienzo, Pigg, & James, 2005; McCabe, 1993; Steutel & Spiecker, 2004). Proponents of sexuality education point to the benefits of implementing such a program, which include decreases in misinformation, increases in accurate information, decreased risk of abuse and exploitation, decreased risk of contracting a sexually transmitted infection (STI), increased self-advocacy skills, increased appropriate sociosexual behaviours, and ultimately, increased social inclusion (Craft, 1994; Demetral, 1981; Di Giulio, 2003; Donovan, 1998; Gerhardt, 2006; Gougeon, 2009; Griffiths, 2003; Kirby, 2000; Sobsey, 1994). The importance of sexuality education specifically for individuals with autism is also well supported in the literature (e.g., Ballan, 2012; Hatton & Tector, 2010; Konstantareas & Lunsky, 1997; Mehzabin & Stokes, 2011; Ruble & Dalrymple, 1993). However, because autism touches on the specific areas of communication, social skills, and behaviour, the educational requirements of youth with autism are different from those of other individuals with cognitive disabilities (e.g., Mehzabin & Stokes, 2011; Stokes & Kaur, 2005; Stokes, Newton, & Kaur, 2007). Individuals with high-functioning autism, while also impacted in these three areas, are affected in different ways than other individuals with autism. As a result, their learning needs are different from neurotypical peers, as well as other disability subgroups, including autism. Consequent to this, individuals with high-functioning autism require learning interventions and content areas that are unique to their specific needs (Davies & Dubie, 2012; Hénault, 2006).

Among concerns related to sexuality for individuals with high-functioning autism are deficits in social skills (Ballan, 2012; Hatton & Tector, 2010; Mehzabin & Stokes, 2011; Nichols & Blakeley-Smith, 2009; Ruble & Dalrymple, 1993) and the display of inappropriate sociosexual

behaviours (Ballan, 2012; Hellemans et al., 2007; Ruble & Dalrymple, 1993; Stokes & Kaur, 2005; Stokes et al., 2007; Tissot, 2009; Van Bourgondien et al., 1997). Compounding this problem is the finding that these individuals are unaware of their engagement in maladaptive behaviours (Hatton & Tector, 2010; Hellemans et al., 2007; Mehzabin & Stokes, 2011). Moreover, studies have shown that this population is challenged in applying knowledge learned in a formal setting into daily life (Hénault, Forget, & Giroux, 2003; Stokes & Kaur, 2005; Stokes et al., 2007). This challenge indicates the need for an effective sexuality curriculum adapted for this population.

In addition to the needs exhibited by individuals with high-functioning autism, societal barriers also impede the sexuality of these persons. Prior research has demonstrated that this population is more likely to have its sexuality medicalized and managed from a disease-perspective (e.g., Galluci, Hackerman, & Schmidt, 2005; Realmuto & Ruble, 1999). Similarly, they may be held to different, more stringent, behavioural standards than their neurotypical peers (e.g., Ballan, 2012; Tissot, 2009). The lack of appropriate, validated, individualized curricula has also been posited as an external barrier (Gilmour, Schalomon, & Smith, 2012; Konstantareas and Lunskey, 1997; Mehzabin & Stokes, 2011; Ousley & Mesibov, 1991), as has a lack of competent educators (Howard-Barr et al., 2005; Kalyva, 2010; Peters, 2007).

Literature on the subject of sexuality and sexuality education for individuals with high-functioning autism has shown that these individuals are interested in sexuality (e.g., Gilmour et al., 2012), but have fewer sexual experiences than the rest of the population (e.g., Mehzabin & Stokes, 2011). Thus, despite interest, their social and sexual deficits and societal barriers prevent many individuals with high-functioning autism from engaging in socially appropriate behaviours, establishing intimate relationships, and being welcomed as equal and valued

members of society (Sullivan & Caterino, 2008; Travers & Tincani, 2010; Tremblay & Pigeon, 2004). The potential consequences of limited social inclusion are far-reaching, and include: depression, anxiety and other mental health issues, low self-esteem, and isolation (Aylott, 2000; Barnhill, 2007; Ghaziuddin et al., 2002; Hatton & Tector, 2010; Koller, 2000; Ozonoff, Garcia, Clark, & Lainhart, 2005).

Clearly, there is a need for adapted sexuality education for youth with high-functioning autism that will help reduce the gap between interest and experience. However, the content of this curriculum remains open for discussion. Historically, the sexuality education curriculum provided in school has addressed more traditional areas of sexuality (e.g., puberty, reproduction, STIs). More recently, steps have been taken to broaden the scope of sexuality education to better reflect the lived realities of students and to better meet their needs. For example, the central policy piece by the Sexuality Information and Education Council of the United States (SIECUS), published in 2004, established guidelines for comprehensive sexuality education. These guidelines continue to be viewed by many as the cornerstone of what sound sexuality education founded on liberal values should look like, and remain well-cited throughout literature on the subject, including in Canadian policy through the Public Health Agency of Canada (PHAC, 2008), for example, and in the area of autism (e.g., Davies & Dubie, 2012; Roth, 2009). In Ontario, attempts to broaden and update the contents of sexuality education have met resistance from some groups, hindering this process (e.g., CBC, 2010; Opeha, 2010).

As the content areas germane to individuals with high-functioning autism generally fall outside more traditional areas of sexuality education, and as moves to broaden the curriculum continue to meet with opposition, the question remains as to how and where these youth can access meaningful sexuality education. Individualized education plans (IEPs) can identify

specialized sexuality education as a goal, though the extent to which this occurs is unknown. When curriculum expectations outlined in IEPs are significantly different from the standardized curriculum provided to the rest of the class, it can be challenging to meet these goals in an inclusive setting. Additionally, it is unclear if educators are sufficiently knowledgeable and skilled in the areas of autism and sexuality to provide such a specialized curriculum. Little research has investigated this area, but results from this sparse literature indicate that educators are not adequately prepared (Kalyva, 2010).

The Ontario curriculum provides suggestions for teaching sexuality education that may be of benefit for neurotypical students, but these suggestions do not necessarily meet the needs of youth with autism. For example, the Ontario Ministry of Education (MEDU) suggested sexuality education topics “are best taught through discussion rather than direct instruction” (2010a; 2010b, p. 31). Students with autism, however, often learn best through explicit and highly structured instruction (Aylott, 2000; Barnhill, 2007; Hatton & Tector, 2010; Sullivan & Caterino, 2008; Travers & Tincani, 2010). Thus, the status of sexuality education for youth with high-functioning autism in school settings remains unclear.

In addition to school-based sexuality education, caregivers are viewed as key providers of sexuality education. In fact, most research supports parents as the *primary* providers of sexuality education, with additional support coming from school and community partners (e.g., Allen, 1987; Blakey & Frankland, 1996; Constantine, Slater, & Carroll, 2007; National Foundation for Educational Research, 1995; Walker, 2004; Wyness, 1992). Despite this view, discourse has tended to conceptualize sexuality education as a formal activity, with much of the focus centred on school-based delivery. And although caregivers are seen as the primary providers, like educators, they neither feel well-prepared nor well-resourced to support their children with

autism (e.g., Ballan, 2012; Nichols, Moravcik, & Pulver Tetenbaum, 2009; Ruble & Dalrymple, 1993).

Some proponents have developed formalized interventions specific to this population (e.g., Davies & Dubie, 2012; Hénault, 2006), though the social validity of their content has not been fully verified with youth and their caregivers. Indeed, across the literature on this subject, there has been very limited research conducted with individuals diagnosed with autism directly, particularly through more qualitative means (see Hatton & Tector, 2010). Also, it is unclear who should be using these curricula. Should schools be using them to provide separate sexuality education to youth? Should caregivers be using them to provide individual formal education at home? Autism Ontario and other community organizations have taken it upon themselves to use these and other curricula to provide sexuality education outside of home and school settings.

Another potential source of sexuality education for youth with autism, including youth with high-functioning autism, may be regional applied behavioural analysis (ABA)-based service providers. The Ontario Ministry of Children and Youth Services (MCYS) launched an expanded ABA-services initiative across Ontario in 2011–2012. This initiative was created in response to the identified gaps in the continuum of ABA services that currently exist for children and youth across the autism spectrum and their families (MCYS, 2011a). The program strives to teach new functional skills and reduce interfering behaviours so that youth can participate more fully in their communities (MCYS, 2011b). Services and supports provided through this program address the domains of behaviour management/emotional regulation, communication, daily living, and social/interpersonal skills (MCYS, 2011b).

This initiative also aims to provide parent education, training, and support in the principles of ABA, as they relate to the domains of behaviour, communication, daily, living, and

social skills. The MCYS recognizes that these areas may overlap or create synergistic effects on each other that require training and education in more than one area concurrently. The domain of sexuality, which touches all four domains of learning, is a good example of how a curriculum may address multiple areas of need simultaneously. Although the MCYS has mandated use of ABA-based interventions for these services, it has not mandated standardized curricula for the four different domains. It is unclear to what extent regional ABA Services and Supports' providers are addressing sexuality education and in what ways. It is also unclear *if* they should be responsible for providing this type of education.

Many unanswered questions exist pertaining to sexuality education for youth with high-functioning autism. Questions go beyond understanding the curriculum. Integral to building this conceptual framework is an understanding of what sexuality education should be, who should be responsible for its provision, and through what modality. In addition, as this population continues to experience a gap between interest and experience, the identification of supports and barriers to sexuality education, understood according to the above dimensions, is also essential. In this sense, this problem touches on issues of curriculum, systems of care, and the broader topic of inclusion. Research is needed that will conceptualize sexuality education specifically for youth with high-functioning autism. Approaches are needed that can compensate for the communicative, behavioural, and social difficulties associated with autism (Mehzabin & Stokes, 2011). Such approaches include qualitative measures that allow for deeper understanding than that available through more traditional, quantitative approaches.

### **Problem Statement**

Previous research has demonstrated that individuals with high-functioning autism are sexual but have fewer sexual experiences than the rest of the population. As a result, they experience more social exclusion (Gougeon, 2010). In addition, they have unique learning

requirements pertaining to their sexuality, yet there is no consensus about the provision and content of such education. Specifically, a dearth of information exists regarding how this adapted sexuality education should look and what its purpose should be. In particular, no research has directly consulted youth with high-functioning autism and their caregivers to understand how they conceptualize sexuality education.

### **Statement of Purpose and Research Questions**

The purpose of this bilingual (English and French) study was to develop a conceptual framework of sexuality education, defined by youth with high-functioning autism and their caregivers, and informed by the literature. In addition, this study sought to identify the personal and societal supports and barriers that facilitate or hinder access to sexuality education for these youth. To respond to this problem, the following research questions were addressed:

1. What does sexuality education mean for youth with high-functioning autism and their caregivers?
2. How do prior literature, policy, and curricula in this field inform this definition?
3. In the context of sexuality education for youth with high-functioning autism, what are the supports and barriers encountered by these youth and what are their impacts?

### **Research Approach**

Upon approval from the Children's Hospital of Eastern Ontario (CHEO) and the University of Ottawa boards of ethics, data were collected from youth with high-functioning autism between the ages of 12 and 18 living in Ontario, and their caregivers. Using a qualitative viewpoint, data were collected primarily through semistructured, in-depth interviews. In addition, surveys completed by youth and caregivers as well as an extant textual analysis were used to support findings obtained through the interviews.

Twenty individuals from eight families were interviewed, including nine youth and 11 caregivers. I conducted all interviews in person and fully transcribed each interview. Interview data were managed, coded, and analyzed with the support of QSR International's NVivo9 qualitative data-analysis software (2010). Written interview transcripts were shared with participants for comment or amendment to enhance trustworthiness (Lincoln & Guba, 1985; Marshall & Rossman, 2011; Seidman, 2006). Qualitative data were coded and analyzed according to research questions and concepts mapped to the theoretical framework, then according to themes and subthemes (Marshall & Rossman, 2011; Patton, 2002). These evolved over the course of the study. Themes between all sources of information were compared and grouped according to main themes/groups and subthemes/groups (Miles & Huberman, 1994).

A total of 14 surveys were completed, including six by youth and eight by caregivers. Quantitative data were managed using SPSS (2009) software. Due to the small sample size, the types of analyses that could be conducted with the data were limited and the power of the statistical tests that were conducted was reduced. Frequencies for all variables in the dataset were calculated.

### **The Researcher**

Of importance to this study is my position as researcher, which is not neutral. In particular, my educational and professional backgrounds colour my interpretations. First, I have a graduate degree in education (intensive special needs) and am a certified teacher, with experience in primarily congregated settings. I am also a board certified behaviour analyst (BCBA). Both educational experiences are deeply rooted in positivist views of learning. I employ principles of ABA in my work and in my daily life. This experience impacts my approach to this study. In my professional experience, I have been working in the field of autism and education for more than 13 years. My professional experience has been quite diverse and has

shaped my socially inclusive perspective. I have worked in community and institutional settings in the Netherlands where individuals generally had their sexuality rights recognized, but other rights were less supported. For example, it was not uncommon for me to meet a happily cohabitating couple with developmental disabilities in a community setting. I also met a mother who was a staunch advocate for her lesbian daughter living with Down Syndrome. On the other hand, it was not uncommon for individuals to be confined to their bed (tied down) or bedroom (externally locked door) at night due to low staffing ratios.

I have worked in an intensive, residential educational program for youth with autism and extremely challenging behaviours in the United States, where high staffing rates allowed for many experiences of social inclusion, but sexuality rights were deemed less important. For example, high staffing ratios allowed for a youth with destructive and aggressive behaviours to gain meaningful employment stocking supplies at a local coffee shop. In contrast, the program had restrictive policies against any type of intimate physical contact between students. As a result, students who lived in this setting had no appropriate sociosexual experiences or education by the time they graduated, usually at 21 years of age. These experiences have shaped my views toward the sexual rights of individuals with disability, particularly individuals with autism.

Most recently, I have gained professional experience as an employee of CHEO's Autism Program of Eastern Ontario, where I work as an administrator for the School Support Program and the ABA Services and Supports Program. The School Support Program works directly with educational professionals from all publicly funded school boards across Eastern Ontario, as well as community partners, to enhance the supports available to students with autism. The program offers training, consultation, and resource development. This program also plays a key role in supporting children's successful transition from publicly funded intensive behavioural

intervention (IBI) to school. The ABA Services and Supports Program provides services aimed at increasing youth engagement, social inclusion, and independence, and improving quality of life (MCYS, 2011b).

In the role of administrator for these programs, I have become familiar with the educational landscape for youth with autism and their families. Interacting with families, school-board personnel, community partners, provincial government, and other stakeholders has increased my understanding of topics germane to autism, education, and in my field of interest, sexuality. Because of my professional experience, I may have been indirectly connected to some participants in this study. Although I do not believe this impacted my position as researcher or the participation or views of participants, I do believe it is important for me to disclose this connection. My education and professional experiences help increase my credibility as a researcher, but also impact my attitudes and beliefs. Attempting to make explicit the implicit subjectivities I hold allows the reader and me to be more aware of their potential effects on the study (Gagnon, 2005; Mertens & McLaughlin, 2004; Stake, 1995).

### **Rationale and Significance**

The rationale for this study comes from a desire to better understand what youth with high-functioning autism seek from sexuality education in order to mitigate their experiences of social and sexual exclusion. Identifying the supports and barriers that impact sexuality education can help bridge the gap between interest and outcome.

This study will give voice to a historically doubly marginalized group. In addition, knowledge obtained through this study can support the development of relevant and meaningful theory, policy, and curricula, which could potentially increase the social inclusion of individuals with high-functioning autism.

## Definitions of Key Terminology

The terms *high-functioning autism* and *Asperger syndrome* are generally viewed as sharing the same fundamental symptomology (Ozonoff, South, & Miller, 2000; Tryon, Mayes, Rhodes, & Waldo, 2006). The recently released *Diagnostic and Statistical Manual of Mental Disorders* (DSM, 5th ed., American Psychiatric Association, 2013) reflected this view and removed Asperger syndrome, which was referred to as *Asperger disorder* in its previous edition (DSM, 4th ed., APA, 1994; DSM 4th ed., text rev., APA, 2000) and incorporated it under the autism-spectrum-disorder umbrella (APA, 2012, 2013). However, as the entirety of this research project took place prior to these new criteria being released, the terms high-functioning autism and Asperger syndrome have been retained. I have done this out of respect for the participants in this study and the ways they conceptualized their autism. In this study, the terms high-functioning autism and Asperger syndrome refer to individuals who have received a diagnosis of one or the other. In general, for ease of reading, the term high-functioning autism is employed. My use of this term is inclusive of participants with high-functioning autism and Asperger syndrome.

Another term adopted with a specific intention for this study was that of *caregiver*. This word was chosen to reflect the diversity of parenting realities encountered in my interviews with families. A combination of parents, parents' boyfriends or girlfriends, step-parents, and grandparents made up the pool of caregiver participants for this study. Thus, the term caregiver encompasses all of these parental roles. To protect the privacy of within-family participants, the generic term caregiver has been adopted in addition to pseudonyms.

*Neurotypical* is a term used in this study to qualify individuals who do not have a diagnosis of autism. This term is used as a more accurate and respectful alternative to the term

*normal* when making comparative statements between individuals with and without autism (National Autistic Society, 2011).

Other terms used in this study that may be unfamiliar to the reader include ABA, IEP, social inclusion, sexual rights, and sociosexual behaviours. Below are definitions for these terms.

*Applied behaviour analysis* (ABA) effectively uses scientifically derived principles of behaviour to systematically change socially important behaviour to a meaningful degree (Baer, Wolf, & Risley, 1968; Cooper, Heron, & Heward, 2007). ABA is comprised of the following seven dimensions: applied, behavioural, analytical, conceptually systematic, technological, effective, and generalizable. It is *applied* in that the behaviours targeted for change must have social significance. ABA is *behavioural* in that it is the study of, not about, behaviour. It is *analytical* in that it seeks to demonstrate control over the behaviour it measures. ABA is *technological* in that the procedures used to modify the target behaviour are fully described so others may replicate them. It is *conceptually systematic* in that it is founded on basic principles of behaviour. ABA is *effective*, meaning it must improve behaviour to a meaningful degree. Finally, ABA is *generalizable* in that behaviour changes must be maintained over time and must generalize across people, settings, and stimuli (Baer et al., 1968; Cooper et al., 2007).

ABA aims to build useful behavioural repertoires and reduce problematic ones. It uses a combination of proactive and reactive strategies to modify behavioural repertoires. Proactive (or antecedent) strategies are those that are presented before behaviours occur, whereas reactive (or consequent) strategies are tactics that are presented following the occurrence of behaviours. Both antecedent and consequent strategies can be effective in changing socially important behaviours (as understood by consumers) to a meaningful degree, and both strategies should be considered when creating ABA-based interventions (Alberto & Troutman, 2006; Cooper et al., 2007).

According to the MEDU, an *individual education plan* (IEP) is a written plan that outlines the special-education program and/or services for a particular student, based on a comprehensive assessment of the student's strengths and needs. An IEP lists the learning expectations that differ from a student's age-appropriate grade level, as well as the accommodations to support the student in meeting these expectations (MEDU, 2004).

*Social inclusion* is a lens used to understand social well-being, equity, and citizenship. A socially inclusive perspective views all children and adults as active, valued, and contributing participants in society (Laidlaw Foundation, 2002). Social inclusion seeks to increase individuals' participation in society by removing barriers and providing supports (e.g., MEDU, 2009). Social inclusion is comprised of various dimensions, including living arrangements, employment, leisure activities, and sexuality. The term social inclusion is discussed in further detail as part of the theoretical framework in Chapter 3.

*Sexual rights* are human rights related to sexuality. Examples of sexual rights are the right to access relevant and appropriate education and information; the right to choose to engage in sexual activity (or not) with oneself or with others; the right to choose to found and plan a family (International Planned Parenthood Federation, 2012)<sup>1</sup>.

*Sociosexual behaviours* are defined as the behaviours exhibited by persons toward other persons that involve sexuality either directly or indirectly. Examples of sociosexual behaviours include flirting, sexting, dating, sexual harassment, kissing, and sexual intercourse. In the context of this study, the term sociosexual behaviour can be positive, negative, or both, whereas the term sociosexual skill generally connotes a more positive (appropriate/acceptable) behaviour. Healthy sexuality is associated with, and often an outcome of, the development and practice of

---

<sup>1</sup> For a recent detailed discussion on sexual rights, see the International Planned Parenthood Federation's (2012) *Sexual rights: An IPPF declaration*.

sociosexual skills. Examples of healthy sexuality include the development of supportive and safe relationships, good self-esteem, and knowledge and skills to avoid STIs.

### **Dissertation Overview**

In this final section of this chapter, an overview of the structure and content of the subsequent chapters of this dissertation is presented. In Chapter 2, additional key terms related to my study are provided, in addition to a thorough review and discussion of pertinent literature. The chapter concludes with the identification of gaps in the literature and ways in which this study bridges these gaps. Chapter 3 begins with a brief discussion of conceptualizations of inclusion, followed by an overview of the epistemological stance I adopt for this research project. Next, the theoretical underpinnings of my research are reviewed. The chapter ends with a proposed theoretical framework of social inclusion, applied in the context of sexuality education. In Chapter 4, the specific context of my current research is provided, including an in-depth explanation of the concept-development model adopted, an overview of the research design, participants, data sources and collection strategies, and analyses. The chapter concludes with a review of the limitations of my study and outlines the strategies adopted to ensure its trustworthiness.

In Chapter 5, I offer a systematic and thorough presentation of seven of the eight central findings of this study. Findings are based mainly on qualitative data obtained through semistructured interviews, with supportive or qualifying evidence garnered from survey data. Using these findings, I offer answers to Research Questions 1 and 3. Chapter 6 offers a thorough presentation of the fourth finding of this study, which informs the first three findings of Chapter 5. This finding is based mainly on related literature, policy, and curricula. This chapter proceeds with a careful analysis of the findings and proposes an answer to Research Question 2. Chapter 7 provides a final analysis, synthesis, and interpretation of the findings according to thematic

categories. These interpretations are then reconsidered in light of the theoretical framework and final findings for each of the research questions are proposed. The chapter then puts forth a refined version of the socially inclusive theoretical framework, subsequent to the outcomes of the study. In the final segment of this dissertation, practical and empirical suggestions are offered. The chapter ends with a discussion of the limitations of the study, along with its primary contributions and final thoughts.

## CHAPTER 2: LITERATURE REVIEW

### Introduction

This chapter begins with the definitions of the following key terms: *disability* (*intellectual* and *developmental*) and *autism*. After this, a detailed review of literature related specifically to sexuality and autism is provided. The chapter ends with a discussion on current gaps in the literature and describes where my research fills these gaps.

### Definitions of Key Terms

**Disability.** Prior to engaging in a discussion on the literature in the field, it is important to arrive at a basic understanding of the key terms being used in this context. Especially germane to the current discussion are the terms *disability* and *autism*. The use of the term *disability*<sup>2</sup> in the literature has certainly been controversial (Boddington & Podpadec, 1991); its definition is context-dependent and has changed over time (Bach, 2004; Brown, 2003). Because the definitions used for specific disabilities are mediated by people and context, and are imbued with values (Fielding, 2004), there are many problems inherent in the identification of who is and who is not included in a disability category (Mertens & McLaughlin, 2004). In addition, disability categories, while useful for classifications, service entitlement, or funding purposes, can have a homogenizing effect that causes individual differences to be ignored (Christensen & James, 2000). This is important when considering prior research related to the sexuality of individuals with disabilities because historically, distinctions have not always been clearly made between various categories and subcategories of impairment, such as intellectual disability and autism (Boddington & Podpadec, 1991; Brown, 2003; Mertens & McLaughlin, 2004). As a result, very

---

<sup>2</sup> For the sake of mutual understanding, I am using the term *disability*, as it is the generally accepted term. However, in describing the theoretical framework proposed for this research project, the term *disability* may be more aptly described as “impairment” with the difference being that an *impairment* refers to the actual biological condition, whereas a *disability* refers to the combined experience of *impairment* and *social barriers* (Reindal, 2008). This definition is discussed in further detail in Chapter 3.

little research has been conducted specifically on sexuality/sexuality education for individuals with autism.

To compound this issue, terminology can vary across location and can mutate over time. The use of the term *mental retardation*, for example, was prevalent in the past to describe individuals with an intellectual disability. This term has now largely been discarded due to its negative connotation (Schalock et al., 2007; Wehmeyer & Obremski, 2013). The term *mental retardation* has most commonly been replaced by the term *intellectual* or *developmental* disability. The terms *learning disability* and *learning impairment* are commonly used in the United Kingdom to describe a developmental disability, however this usage is less common in North America where the terms *learning disability* and *learning impairment* are more often used to describe impairments that are not intellectual in nature (e.g., dyslexia or dyscalculia; American Association on Intellectual and Developmental Disabilities [AAIDD], 2008; Schalock et al., 2007). Nonetheless, the term *learning disability* is sometimes considered a subcategory of a developmental disability (e.g., Boyle et al., 2011).

Currently, the terms *intellectual* and *developmental* disabilities are used interchangeably by certain organizations (e.g., Community Living Ontario, 2013). However, this use is not unanimous, and a more common view is one that recognizes a distinction between the two types of impairments. The AAIDD (2013) defined developmental disability as a severe, chronic, often lifelong condition that appears before the age of 22. It also categorizes developmental disability as an umbrella term that includes intellectual and various other disabilities (AAIDD, 2013). Locally, the MEDU (2001) distinguished intellectual from developmental disabilities in a different manner, delineating differences primarily according to severity. A mild intellectual disability is defined as a learning disorder that allows a student to (a) benefit academically in a

regular classroom with supports and a modified curriculum; (b) not benefit academically in a regular classroom because of slow intellectual development, or (c) have the potential for academic learning, as well as social and economic independence. A developmental disability is characterized by the MEDU as a severe learning disorder that allows a student to (a) not benefit academically in a special-education program for individuals with an intellectual disability because of slow intellectual development; (b) benefit from a special-education program designed for slow intellectual development; and (c) have limited potential for academic learning, as well as social and economic independence.

According to the *International Encyclopedia of Rehabilitation*, intellectual disabilities are necessarily also developmental disabilities because they manifest themselves during the developmental period, which occurs prior to 18 years of age (Wehmeyer & Obremski, 2013). Whereas a developmental disability can affect cognitive and/or physical functioning, an intellectual disability pertains only to impairment of cognitive functioning of an individual (AAIDD, 2013). Thus, it is possible for an individual to have a developmental disability without necessarily also having an intellectual disability. This last point is particularly relevant when discussing disability and autism and the impact of categorization on research, as I discuss next.

**Autism spectrum disorders.** *Autism Spectrum Disorder (ASD)*<sup>3</sup> or *autism* is a unique lifelong neurodevelopmental disorder. The term *autism* was first coined by Bleuler in 1911; however, its more familiar meaning and use did not begin until the 1940s by researchers such as Kanner (1943; Grinker, 2007). Autism has affected an increasing number of families, as its prevalence has escalated dramatically over the past few decades, from estimates of around 1 in 1,000 in 1988 (Bryson, Clark, & Smith, 1988) to estimates of about 1 in 110–200 more recently

---

<sup>3</sup> Unless stated otherwise in the text, I will use the term *autism* to inclusively mean *autism spectrum disorder*, *Asperger syndrome*, and *Pervasive Developmental Disorder–Not Otherwise Specified*.

(Centers for Disease Control and Prevention [CDC], 2010; Fombonne, Zakarian, Bennett, Meng, & McLean-Heywood, 2006). The CDC has estimated rates as high as 1 in 88 (Baio, 2012). The origins of autism are unclear, however most experts concur that biologic, genetic, and environmental factors are involved (CDC, 2010). Autism affects males more than females at approximately a 4:1 to a 5:1 ratio (Baio, 2012). Similar statistics have been reported for male to female ratios of Asperger syndrome. Recent research has pointed to the possibility that Asperger's syndrome affects males even more markedly than females with a male:female ratio as high as 12:1 (Whiteley, Todd, Carr, & Shattock, 2010).

All individuals with autism must meet the following diagnostic criteria<sup>4</sup>: qualitative impairments in social interactions and communication; restrictive repetitive stereotyped patterns of behaviour; delays or abnormal functioning before Age 3 in social, communicative, or imaginary play (APA, 2000). These criteria are also known as the *triad of impairments*. Impairments in these areas can have significant functional effects over the span of an individual's lifetime. Because autism is a spectrum disorder, it manifests in various ways and can present any number of characteristics. These characteristics can range from very mild (e.g., Asperger syndrome or *high-functioning* autism), to very severe (e.g., *classic* autism or pervasive developmental disorders) (Geschwind, 2009; Ruble & Dalrymple, 2002). Variability can be observed in speech and language, autonomy, cognitive abilities, activities of self-care, social skills, behaviour, and comorbidity with other conditions (e.g., Jasmin, Couture, McKinley, Reid, Fombonne, & Gisel, 2009; Montalbano & Roccella, 2009; Ronald & Hoekstra, 2011). Due to the heterogeneity inherent in autism, each person requires an individualized approach to intervention (e.g., Olley, 1999; Ruble & Dalrymple 2002; Ruble & Sears, 2000). Further, because social and

---

<sup>4</sup> At the time of the participant recruitment, data collection, analysis, and writing of this document, the *DSM-V* (APA, 2013) had not yet been released. For this reason, *DSM-IV* diagnostic criteria and nomenclature have been retained throughout this document.

communication deficits are two hallmarks of autism, effective sexuality education necessitates emphasis on the social aspects of sexuality. However historically, social skills have been minimized or excluded from more traditional sexuality curricula.

It is estimated that about 70% of individuals diagnosed with autism also have an intellectual disability; conversely, 40% of individuals living with an intellectual disability also have autism (e.g., Ghaziuddin, Ghaziuddin, & Gredden, 2002; La Malfa, Lassi, Bertelli, Slavini, & Placidi, 2004). Thus, a correlation exists between intellectual disability and autism. Yet particular characteristics of autism result in learning needs that are significantly different from learning needs associated with an intellectual disability alone. For example, individuals with autism present unique characteristics and skill deficits that often require targeted training of skills. These skills are part of the *hidden curriculum*—those unwritten and unspoken rules which are learned incidentally or naturally by other individuals (Gougeon, 2009; Lavoie, 2005; Smith Myles & Simpson, 2001).

Impairments in the areas of verbal and nonverbal communication often present this population with particular difficulties in successfully navigating social situations. Individuals with autism are often unable to “read” a person’s facial expression, and may be overly reliant on verbal content that may be inconsistent with a nonverbal message (e.g., Lindner & Rosén, 2006). They also have a tendency to comprehend language at a literal level and do not process intonation properly (Rogers, 2000). In addition, they often lack *theory of mind*—the ability to understand perspectives different from their own (e.g., Baron-Cohen, 2001; Chin & Bernard-Opitz, 2000). Consequently, they may be viewed as socially awkward, rude, or inappropriate.

Because of their deficit in decoding interpersonal situations they may engage in socially inappropriate behaviours. They may tend to have difficulties establishing and maintaining peer

relations because of their deficits in social skills, including difficulties in mastering basic conversation pragmatics. This population tends to have a narrow area of interest; resulting conversations may be one-sided with little engagement of the listener (Hénault, 2006). These social issues make successful relationship-building extremely difficult. Moreover, individuals with autism often have sensory issues that can affect their tactile experiences through hyper- or hyposensitivities (Davies & Dubie, 2012; Hatton & Tector, 2010; Hénault, 2006). As a result, some forms of touching and other intimate physical interactions can be aversive for the individual with autism. This problem is often compounded by an individual's communication impairments and other characteristics such as repetitive nonfunctional behaviours or self-stimulation (Gray, Ruble, & Dalrymple, 2000; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Hénault, 2005, 2006; Howlin, 2004). Consequently, it can be difficult for others to understand and manage intimate relationships with persons with autism (Hénault, 2006; Lawson, 2005). These factors, taken in conjunction, create unique needs and challenges in the sexuality and sexuality education of individuals with autism.

Moreover, individuals with high-functioning autism have an intellectual ability that falls within the average to above-average range, whereas individuals on the more severe end of the autism spectrum often present with an intellectual disability (Ghaziuddin et al., 2002; La Malfa et al., 2004), have more pronounced communication deficits, and are more likely to engage in unusual or aberrant behaviours such as self-injury, aggression, or self-stimulation. As such, the needs of individuals with high-functioning autism differ from other individuals with autism (with intellectual disability comorbidity), as well as from individuals with an intellectual disability alone. For the purposes of this study I adopted the following definition of high-functioning autism/Asperger syndrome: a developmental disability that includes the triad of impairment

(behaviour, communication, and social skills), as well as average or above-average intellectual ability. It does not include intellectual disability. It may or may not include other comorbidities (e.g., ADHD or bipolar disorder).

The aforementioned categories or labels become problematic when seeking to review prior literature on the subject of sexuality and sexuality education for youth with high-functioning autism, because previous research often did not distinguish between categories of impairments such as *developmental disability*, *intellectual disability*, *autism*, and *high-functioning autism/Asperger syndrome*. As a result, it is unclear which research findings apply to this population. Research in the field of sexuality education for individuals with disabilities overall has a long and vast history; however, the needs and strengths of youth with high-functioning autism in the area of sexuality education are unique and therefore merit further specific investigation. The main purpose of this literature review is not to repeat what has been studied and reported in the past, but rather to highlight available research that provides background and context to this study. Because research specifically on the topic of sexuality education for individuals with high-functioning autism is quite new, it is necessary to survey literature on the subject of sexuality and autism more broadly, in addition to the current context. I address this topic in the following section.

### **Research on Sexuality and Autism**

To address the specific area of focus of my research project, a formalized and systematic literature search and review was deemed necessary. Initially, I used the key words *autism* or *Asperger* paired with either *socio-sexuality*, *sex/education*, or *sexuality/education* to search the following databases: Academic Search Complete, CINAHL, Education Full Text, Educator's Reference Complete, ERIC, MEDLINE, and PsycINFO. Internet-based search engines such as Google Scholar were also employed. I sought research articles published between 1990 and

2010<sup>5</sup> in peer-reviewed journals. Once this was completed, I conducted a second search, consulting primary sources cited in the pertinent articles, based on their relevance to the subject, as well as meeting the aforementioned criteria. The resulting initial and comprehensive literature review was published in the *American Journal of Sexuality Education*, and can be found in Appendix A (Gougeon, 2010). Between August 2012 and April 2013, the process was periodically repeated and the literature review was updated to include research on sexuality education interventions and to reflect the latest research developments. As a result, only those studies that are central to the current discussion are included for analysis in this chapter; all other relevant studies cited in this chapter are explored further in Appendix A, which includes a summary table of reviewed research.

An important note on the structure of the literature review provided in this document is necessary at this point. As identified in the introductory chapter, the second research question of this study required a literature review to inform the data obtained through the first research question. Consequently, the literature review offered in this thesis is somewhat unconventional in that it occurs partly in two phases. The initial literature review provided in this chapter addresses prior research on the sexuality/sexuality education of individuals with autism. The primary purpose of the review is to compare and contrast research according to methodology (quantitative versus qualitative) and according to subject/participant (individual with autism or other), or according to intervention (for applied studies). In the discussion, I identify and consider the individual and societal barriers that currently exist that impede sexuality education, which is related to the third research question. I identify the gaps in the research and situate my

---

<sup>5</sup> This timeframe was chosen to reflect the history of the use of the term *autism*. It was not until 1987 that a definition of *autistic disorder* similar to the one used today was added to the *DSM III-TR* (APA, 1987). Prior to 1987, autism was categorized as *infantile autism* (*DSM III*, APA, 1980) and *schizophrenia: childhood type* (APA, 1952, 1968; see also Grinker, 2007).

study in the current context, to bridge some of these gaps. The second phase of the literature review specifically addresses the areas of sexuality education form and content from research, policy, and practice perspectives. This phase occurs in Chapter 6.

Studies retained for this review varied by method, sample size, location, and focus. The ensuing section provides a summary of the salient research covered in the critical literature review, as well as those added between 2012 and 2013, according to their major findings and implications. In addition, a table summarizing key information for each study can be found in Table B1 in Appendix B. Following a review of the research, I discuss key themes related to my study: importance of sexuality, problematics of sexuality, issues of translation, and considerations of sexuality education.

**Quantitative research: Perceptions of others.** There has been limited research on the sexuality and sexuality education of individuals with high-functioning autism. Most research on sexuality and disability, including about individuals with autism, has historically been rooted in the positivist tradition. Of the studies found as part of the literature search for this study, a vast majority adopted quantitative methodologies; in particular, survey methodology was most common (Hellemans et al., 2007; Kalyva, 2010; Ruble & Dalrymple, 1993; Stokes & Kaur, 2005; Stokes et al., 2007; Van Bourgondien, Reichle, & Palmer, 1997). Additionally, the sexuality of individuals with autism has most often been studied from an etic perspective, with most research seeking the views of people who care for individuals with autism, rather than these individuals themselves.

Among studies assessing the perceptions of others, some focused on the views of professionals, whereas others have focused on parents. For example, Van Bourgondien et al. (1997) used a survey methodology to examine residential carers' views of the sexual behaviours

and knowledge of individuals with autism, as did Hellemans et al. (2007). In the former study, a survey was conducted with residential workers caring for individuals with autism aged 16 to 59. The study examined residents' sexual behaviours and sexuality policies in these residences. Hellemans et al. (2007) sought input from caregivers of individuals with autism (aged 15 to 21) living in institutional residences. The study looked at a range of individuals' sexual knowledge and behaviours.

Both studies revealed that sexual interest toward others exists in this population. They also found that individuals with autism exhibit sexual behaviours, experience sexual frustration, and some demonstrate inappropriate sexual behaviours. The authors reported that some programs provide sexuality education to individuals with autism, though Van Bourgondien et al. (1997) discovered that few programs provide related training to their staff. Further, only a small minority of programs allow individuals to engage in shared sexuality. In Hellemans et al. (2007), the authors found that individuals with autism were limited in their ability to apply the sexual knowledge they had acquired through formal sexuality education provided to them. Results also indicated a variety of sexual behaviours related to what the authors deemed "autistic features" (e.g., sensory or object preferences). In addition, almost a third of individuals were reported as having "severe sexual problems." Both studies were limited by the lack of self-report from individuals with autism themselves or the lack of observational data. The functioning level of the individuals investigated in both studies also limited the generalizability of the findings to other individuals with higher functioning autism.

More recently, a study by Kalyva (2010) examined teacher perceptions toward the sexuality education of students (aged 7 to 14 years) diagnosed with autism. Using a survey methodology, the study examined children's social behaviour, privacy, sexuality education, and

sexual behaviours. It was found that only a small minority of teachers (12.5%) felt confident in their ability to provide appropriate sexuality education to their students with autism. Appropriate sociosexual skills were perceived by teachers as positively correlated to student functioning, as was sexual knowledge and understanding. However, teachers expressed more concern about the social and sexual futures for their higher functioning students than for those on the more severe end of the spectrum. Limitations of this study included lack of parental, self, or peer input; confining the study to students with autism who lived with their families; the limited generalizability of the findings, as youth may display different behaviours in different settings; possible confounding effects of support from mental health professionals for most youth included in the study; the absence of functioning level as inclusion/exclusion criteria as well as reporting on functioning level as part of the study; and limitations inherent to the tool.

Other research has focused on the perceptions of parents toward their children's sexuality or sexuality education. Ruble and Dalrymple (1993), for example, used a survey methodology to examine parents' perspectives on this subject for their children aged 9 to 39. They found that verbal skills were seen to be positively correlated with knowledge and understanding of sexual topics. However, regardless of verbal abilities, a variety of more and less appropriate sexual behaviours were reported. Parents were most concerned about their children's nonsexual behaviours being misinterpreted as being sexual, followed by concerns about pregnancy and sexual abuse. Finally, although parents reported having taught a variety of skills to their children, they remained concerned about how to effectively teach sociosexuality education to their children. One limitation was the broad range of the ages of children included in this study. This wide range (9–39) may have impacted the variety of responses obtained from parents. Also, most respondents were mothers, which may have affected the responses obtained.

Two studies surveyed parents of children with high-functioning autism or Asperger syndrome and compared them to parents of neurotypical children (Stokes & Kaur, 2005; Stokes et al., 2007). In both studies, it was found that youth with high-functioning autism had lower social and sexual functioning than their neurotypical peers overall. In Stokes and Kaur's (2005) study, which assessed the perceptions of parents of children aged between 10 and 15 years, neurotypical youth had an increase in sociosexual knowledge and behaviour as they aged, whereas this was not true for individuals with high-functioning autism. In the Stokes et al. (2007) study, parents of individuals between the ages of 13 and 36 years were surveyed on their perceptions of their child's sexuality. As in the former study, youth with autism were less likely to learn social and sexuality skills from peers than neurotypical individuals, though increased skills and knowledge from peers predicted increased social functioning. Of concern was the finding that individuals with autism displayed a variety of inappropriate or "stalking" types of behaviour that their neurotypical peers did not.

Interestingly, it was found that parents of children with autism in the Stokes and Kaur (2005) study became increasingly concerned about their social and sexual outcomes as they aged. The same finding was not true for parents of neurotypical children. The authors identified a developmental lag in youth with high-functioning autism that translates into sociosexually inappropriate behaviours, as well as gaps in understanding. Although the authors hypothesized that this gap may decrease as individuals with autism mature, more recent research on adults with high-functioning autism negated this hypothesis (Mehzabin & Stokes, 2011). A limitation of both studies could be found in the use of novel instruments that require further refinement and validation. Another limitation was the small participant sample of parents of children with

autism, which limited the generalizability of the results. Both studies also lacked input from youth themselves to further validate or qualify data obtained from parents.

**Quantitative research: Self-perceptions.** Few studies have used self-reporting to investigate sexuality/sexuality education with individuals diagnosed with autism. Of the little research that has been conducted with individuals with autism on the subject, most has favoured quantitative methodologies. Some researchers have cited that obtaining meaningful information from this population can be difficult because of the communication deficits that are a hallmark of the disorder (Realmuto & Ruble, 1999); others have called for more research, stating that further understanding of this phenomenon is needed (Mehzabin & Stokes, 2011).

Studies that have examined the self-perceptions of individuals with autism have helped dispel myths surrounding their sexuality. Among them, research conducted by Ousley and Mesibov (1991) and Konstantareas and Lunskey (1997) compared the sexual knowledge and attitudes of individuals with autism to those with an intellectual disability alone. In Ousley and Mesibov's study, knowledge, interest, and experience relating to sexuality and dating in adults with autism were assessed and compared to those of individuals with a mild to moderate intellectual disability. Researchers used a questionnaire to interview participants on sexual vocabulary to assess knowledge, as well as sexual and dating experiences and interest in sexual activities. Men in both groups were found to have a higher level of interest in sexuality and dating than their female counterparts. Sexual knowledge and interest were the same for both comparison groups (autism and intellectual disability). However, individuals with autism had significantly less sexual experience. A limitation of the study was the small sample size. Another potential limitation was the use of an adapted tool that was originally developed for use with

individuals who have an intellectual disability. Finally, a constraint of the study was the lack of comparison between individuals with autism and neurotypical individuals.

A study by Konstantareas and Lunsky (1997) also assessed the sexual knowledge, interest, and experiences of individuals with autism and compared them to individuals with an intellectual disability. The study used a questionnaire and interview to address topics similar to those covered in the Ousley and Mesibov (1991) study. Although there were no differences in results based on cognitive-functioning level that were attributable to group or gender, individuals with autism scored significantly lower in social and communication functioning. Both groups showed awareness of sexual vocabulary, though many also showed lack of understanding of this vocabulary. A low participation rate was a limiting factor of this study, as was the limitation of the sensitivity of the instrumentation in measuring knowledge and behaviour. As in the Ousley and Mesibov (1991) study, no comparison was made between the study's samples and neurotypical individuals. The stability of participants' responses over time would also be of use in this area.

Findings from both of the studies cited above included similar levels of knowledge, as well as similar levels of interest in sex across groups. In research by Konstantareas and Lunsky (1997), the authors found that individuals had limited understanding of the terminology related to sexuality. Also, the study found an inverse relationship between attitude toward sexuality and amount of knowledge received. They posited that this may have been a consequence of the discourse of fear and protection associated with sexuality information for these groups. Ousley and Mesibov (1991) found that individuals with autism had less sexual experience than the comparison group, which may result in increased sexual frustration that can cause maladaptive sexual behaviours. However, more recent research has not supported this assertion (Van

Bourgondien et al., 1997). The authors of these studies recommended adapted sexuality education to address the issues raised.

Relevant to the current context was a recent study by Mehzabin and Stokes (2011) comparing the sexuality of young adults with high-functioning autism and their neurotypical peers. Results showed that individuals with high-functioning autism had lower levels of sexual experience, as well as lower levels of social and sexual behaviours. These findings are concerning because, in contrast to speculations in previous research (Stokes & Kaur, 2005), a wide sociosexual gap between individuals with autism and their neurotypical peers persists into adulthood. An unexpected finding was similar self-reported levels of privacy-seeking behaviours in both groups. The authors hypothesized that this may be due to limited self-awareness on the part of individuals with autism. Of particular interest was the finding that individuals with high-functioning autism had heightened levels of anxiety toward their future, especially with regard to their behaviour being misinterpreted by others, as well as finding a romantic partner. Because of limited self-awareness displayed by individuals with autism, the authors identified the self-report questionnaire methodology as a limitation of their study. They suggested that future research triangulating reports from individuals with autism, their caregivers, and possibly observational data would be useful in addressing the limitations of self-report or caregiver report alone. The authors also recommended early targeted sexuality education focused on social skills for individuals with high-functioning autism.

Recent research studying the sexuality of individuals with autism has continued to support the finding that these persons are generally sexual, though the sexuality they experience and exhibit may fall outside the norm to some extent. For example, Gilmour et al. (2012) looked at the sexual attitudes and behaviours of adults with high-functioning autism and compared them

to neurotypical adults through the use of online survey methodology. Consistent with previous research, it was found that individuals with high-functioning autism are interested in sex and display sexual behaviours. The breadth and strength of their sexual behaviours were similar to that of neurotypical individuals. They also displayed levels of theoretical knowledge equivalent to their neurotypical peers. However, the study also found higher rates of asexuality across both genders and lower rates of heterosexuality for women among participants with high-functioning autism. One limitation of this study was that participants self-selected their involvement in the study, which may have biased the responses according to interest in the subject. Another important limitation was the high rate of female participants with autism compared to male participants (55:17). This gender ratio is not representative of the ratio that occurs in the larger population. Consequently, the generalizability of the findings is limited. A last limitation is the quantitative methodology employed, which prevented further probing with those individuals who self-identified as asexual to better understand their conceptualizations of asexuality and their motivations to respond in the ways they did.

**Qualitative research: Perceptions of others.** Most research on autism, including research about sexuality and sexuality education, has prioritized quantitative methodologies. However, some research has been conducted that adopted a qualitative approach. Two studies, in particular, examined the etic perspective from a primarily or wholly qualitative standpoint.

A mixed-methods study by Nichols and Blakeley-Smith (2009) examined parents' views toward their children's (aged 8–18) sexuality, and evaluated a parent sexuality training program. A focus group produced themes used to develop the parent-education curriculum. Parents in the study held mixed feelings about their children's long-term social and sexual outcomes. Echoing previous research, parents expressed fear of abuse and exploitation, as well as the

misinterpretation of behaviours and their potential legal ramifications (Kalyva, 2010; Mehzabin & Stokes, 2011; Ruble & Dalrymple, 1993). In addition, parents identified the need to educate community stakeholders in addition to addressing their children's sexual educational needs. One limitation of this study was the lack of a control group. A second potential limitation was the diversity of the functioning levels of children represented in the study, which may have resulted in different parental educational needs. Also, parents self-selected their participation in this study, which may have biased the results. For example, high levels of comfort were expressed by parents prior to engaging in the training portion of the study, indicating potential bias related to participant self-selection. Another limitation of the study was the lack of specific goals for participants, as well as lack of specific goal measurement. Youth progress was also not considered as part of this study. A final limitation was the lack of parental competence as a goal of the program.

Most recently and most relevant to the current context was a wholly qualitative study conducted by Ballan in 2012 with parents of children (aged 6 to 13) across the autism spectrum. Semistructured, in-depth interviews were conducted with these parents on the topic of sexuality education. Four content-related themes were identified as a result of the interviews conducted with parents. The first theme concerned misperceptions about children's sexual and nonsexual behaviours, a recurrent theme in the literature. Parents attributed this issue to a deficit in their children's skill, as well as a lack of awareness and understanding by others toward autism. A second theme involved challenges discussing sexuality with children and professionals. Parents were concerned that information they communicated to their children would be misunderstood, including topics being inappropriately overgeneralized. One fear mentioned by parents was that of children fixating on aspects of sexuality if the topic was raised. Parents also noted a gap

between their child's emotional and chronological maturity. For these reasons, many parents had little or no communication on sexuality with their children. As to professionals, parents described sexuality for their children being treated reactively and only from a problem-based perspective. Some also mentioned the use, though limited, of other parents as resources to fill the professional gaps.

Another theme that emerged from the interviews was that of sexuality information communicated with children. Parents reported communicating with children mostly on abuse prevention and personal hygiene. Parents reported being concerned that the information and guidelines they provided to their children may have been too complicated or contradictory for them to apply. They also reported using discussions about personal hygiene as teachable moments with their children.

A last emergent theme was that of parental perceptions of children's future. There was disagreement among parents regarding when sexuality education should take place. Parents of younger children reported education should take place in later elementary years, while parents of older children reported education should take place in early elementary years. Parents believed they should be educators for their children in the area of sexuality; however some parents believed they should be the primary educator whereas others saw the responsibility as being shared between them and school or medical professionals. Another finding was that parents did not foresee a future for their children that included them being appropriately sexually active. The researcher concluded that the development of a curriculum targeting the needs of parents on sexuality education for their children with autism is needed. Such a curriculum should be based on evidence-based practices such as ABA or social stories. One limitation of this study was the small size of the sample. Also, parents self-selected their participation in this study, which may

have biased the results to some degree. Another potential limitation of the study was the age range of youth being studied (6 to 13), as sexuality needs may have been quite disparate among these children. Also, no functional level was reported for these children, which may also have resulted in divergent parental responses.

**Qualitative research: Self-perceptions.** Although the bulk of the research conducted on the topic of sexuality/sexuality education for individuals with autism has favoured quantitative methodologies and the voices of others, researchers have adopted qualitative methodology and privileged the voices of individuals with high-functioning autism. In a primarily qualitative, mixed-methods study, Hatton and Tector (2010) used surveys from 12 adults with high-functioning autism who had attended a specialized residential school on their experiences of sexuality education. Among the survey participants, four agreed to partake in semistructured interviews (three in person, one by e-mail) on the topic. Findings from these sources were combined with findings from a literature review on the subject. The authors used all three sources to create a sexuality curriculum. Findings from the surveys and interviews revealed that the former students felt their education lacked a relationship component, which continued to affect them in their adult lives. Interviews also revealed that participants would have benefited from learning about their autism and its impact. Participants also demonstrated knowledge about sexuality, but had limited ability to apply this knowledge. Additionally, it was found that sensory issues acted as a barrier to establishing relationships with others. Using these findings, the authors created a curriculum that was founded on self-awareness (which included autism awareness), understanding, and self-esteem. Among the limitations of this study were the small sample size and the lack of clear articulation of the processes involved in the literature review and the qualitative data analysis. The study also did not disclose the genders of the participants

or other demographic information, which impacts replication and generalizability. Also, the data relied on participants' recollections of experiences while at school. These recollections may have been more or less accurate because of the elapsed time since the experiences occurred.

**Sexuality education interventions.** Few studies have actually examined the efficacy of a sexuality curriculum for individuals with high-functioning autism/Asperger syndrome or those providing sexuality education to them. Although not specifically for parents of youth with high-functioning autism or Asperger syndrome, the previously mentioned study conducted by Nichols and Blakeley-Smith (2009) evaluated an 8-week sexuality education program for parents of children with autism. Following the training component of the study, parents had increased their comfort and knowledge in addressing sexuality with their children. Parents also reported being able to create and meet personal objectives related to sexuality education for their children, including identifying members of their child's sexuality education team developing a sexual learning plan for their child. However, whether parents applied their new knowledge and skills was not assessed.

Research conducted by Tissot (2009), which employed case-study methodology, looked at students with autism who attended a residential school and examined their need for establishing what Tissot referenced as a "sexual identity." The study examined the school's interventions of "sexual problems." Problem behaviours included being distressed about menstruating, problems related to masturbation, and students seeking reciprocal same-sex relationships. The following six-step program was employed: reviewing school policy and procedures, consulting with multiple stakeholders, implementing sexual-health curriculum, disseminating support strategies among stakeholders, providing ongoing support, and review.

Problematic behaviours (as defined by the researcher) were reduced and appropriate behaviours were increased for the vast majority of students.

In a doctoral thesis completed by Hénault (Hénault et al., 2003), a group-based sociosexual program for individuals with high-functioning autism/Asperger syndrome was implemented and evaluated. The program consisted of 12 weekly workshops and was adapted from Durocher and Fortier's (1999) *Programme d'éducation sexuelle*. The program was found to be effective in increasing participants' sexual knowledge and positive attitudes toward sexuality. Individuals also increased their social and intimacy skills while decreasing inappropriate behaviours. These gains were generally maintained 3 months following the intervention. Although individuals increased some skills related to theory of mind, these were limited. Further development and use of additional supports to address needs in this area were recommended. Another limitation was the potential for limited generalization postintervention. It is recommended that a multistakeholder support system be put in place to help generalize the gains attained through the workshop into daily life.

In a master's thesis completed by Roth (2009), a group-based program teaching a psychosexuality curriculum to six adolescent boys with high-functioning autism and their parents was evaluated. Roth employed both quantitative and qualitative data-collection methods. Results showed positive general overall outcomes, with increased comfort and goal attainment for some families. However, significant changes were neither found regarding increases in sexuality knowledge for youth nor for parental worry and acceptance of their child's sexuality. This study was limited by its small sample size, its lack of a control group, and its lack of generalization and maintenance over time. The author also identified the use of a youth self-report questionnaire for behaviour change measurement as a limitation, because youth with autism often have limited

self-awareness that may impede on their ability to accurately assess changes in behaviour (Mehzabin & Stokes, 2011; Mitchell & O’Keefe, 2008; Roth, 2009).

## **Discussion**

**Importance of sexuality.** Some common themes emerge from these studies that are relevant to the current context. First and foremost, all of the research clearly demonstrates that individuals with autism are sexual. As reported by individuals themselves, most are sexually interested in others and engage in a range of sexual behaviours, adding to the growing body of evidence disputing the myth that all individuals with autism are asexual (e.g., Ballan, 2001, Gilmour et al., 2012; Hatton & Tector, 2010; Konstantareas & Lunsky, 1997; Marriage, Wolverton, & Marriage, 2009; Ousley & Mesibov, 1991). Indeed, most individuals with autism are sexual, though this sexuality may be expressed in different ways (Gilmour et al., 2012; Konstantareas & Lunsky, 1997; Ousley & Mesibov, 1991). In other words, sexuality matters. Although sexuality is a reality for individuals with autism, many have had limited sexual experiences (Hénault & Attwood, 2002; Mehzabin & Stokes, 2011; Ousley & Mesibov, 1991) and therefore encounter sexual frustration and anxiety (Hellemans et al., 2007; Mehzabin & Stokes, 2011; Ousley & Mesibov, 1991; Van Bourgondien et al., 1997). In addition, individuals with high-functioning autism experience poorer long-term social outcomes (e.g., Barnhill, 2007, Howlin, 2000). These outcomes may be the result of personal and external barriers. In the following section, I explore some potential barriers that may impede the sexuality and sexuality education of individuals with autism, identified in the research.

**Problematics of sexuality.** A common theme in the research was the identification of personal-skill deficits as well as inappropriate behaviours by parents and professionals that negatively impacted the sexuality or sexual education of individuals with autism. For example, parents and professionals overwhelmingly stated that individuals with autism demonstrate a

combination of skill deficits and inappropriate sexual behaviours. The skill deficits exhibited by these individuals can result in nonsexual behaviours being perceived as inappropriate sexual behaviours (Ballan, 2012; Nichols & Blakeley-Smith, 2009; Ruble & Dalrymple, 1993). This concern was echoed by individuals with high-functioning autism as well (Hatton & Tector, 2010; Mehzabin & Stokes, 2011). Such skill deficits indicate the need for an effective sexuality curriculum adapted for this population.

In addition to nonsexual behaviours being misconstrued as sexual, individuals with autism do sometimes display inappropriate sociosexual behaviours (Hellemans et al., 2007; Ruble & Dalrymple, 1993; Stokes & Kaur, 2005; Stokes et al., 2007; Van Bourgondien et al., 1997). Such behaviours include compromised privacy (e.g., not closing the door when using the bathroom, removing clothes in a public area), practicing poor personal hygiene (e.g., not brushing teeth regularly, not using deodorant when needed), not respecting personal boundaries (e.g., standing too close when speaking to someone; touching a stranger), as well as more concerning stalking behaviours such as following, repeated attempts at establishing contact, and monitoring others (Ballan, 2012; Stokes & Kaur, 2005; Stokes et al., 2007; Tissot, 2009). Compounding this issue, individuals with autism are not aware of the inappropriateness of their behaviours (Hatton & Tector, 2010; Hellemans et al., 2007; Mehzabin & Stokes, 2011). As these maladaptive behaviours can impede individuals' opportunities to initiate, develop, and maintain intimate relationships with others, it seems important to create effective ways to address this lack of self-awareness, as well as to provide effective means of teaching appropriate replacement skills.

However, the view that inappropriate behaviours rest entirely on the shoulders of individuals with autism may be somewhat nearsighted. On this subject, parents in Ballan's

(2012) research discussed how sexual behaviours appropriate for nondisabled children are perceived by others as aberrant in children with autism. This issue relates to the external barrier of judgment and what can be termed the problematic sexuality of individuals with autism (Gougeon, 2010). Indeed, the discourses adopted in some of the research underscore the medicalization of sexuality for individuals with autism (see Galluci et al., 2005; Realmuto & Ruble, 1999) and have been associated with the phenomenon of *counterfeit deviance* (Hingsburger, Griffiths, & Quinsey, 1991). In Tissot (2009), for example, sexuality education is provided to students who present with “problematic” sexual behaviours. One of these behaviours is defined as a same-sex relationship between two consenting male students. The reported “successful” education plan involved preventing a relationship from taking place. This outcome was the result of school policy and parent preference. However, such sexual behaviour is not problematic and the intervention, although deemed successful, is discriminatory. These types of sexuality education perpetuate individuals with autism being denied the ability to fully enjoy their sexual rights (Watson, Venema, Molloy, & Reich, 2002). Such a program is couched in a discourse of care by calling its education program a “sexual identity program” (Tissot, 2009), when in this instance it acts as a program that negates sexual identity.

Another example of how judgment can impact assessment of sexual behaviour for individuals with autism can be found in Van Bourgondien et al. (1997). This study viewed certain idiosyncratic “autistic” sexual behaviours as problematic. Such behaviours were generally associated with sensory particularities. Although an argument can be made that some extreme or dangerous behaviours may be problematic, the particularities in many instances fell in the range of “normal” for the rest of the population (Love, 2004). That sensory-based particularities are problematic because they are “autistic” may be conflating issues, as many safe

preferences can appropriately be manifested in private. Thus, the issue is about teaching safe and appropriate privacy behaviours, not about eliminating individual preferences. Similarly, Hellemans et al. (2007) identified a third of the study sample as having “severe sexual problems,” yet upon closer investigation, most problems were related to issues of privacy.

Negative discourses around the sexuality of individuals with disabilities are equated by some as problems of unhealthy systems and can have negative consequences (e.g., Hingsburger & Tough, 2002). As exposed by Konstantareas and Lunsky (1997), sometimes individuals who receive more information about sexuality view it negatively as a result of a discourse of fear. Such a discourse is prevalent in discussions about sex with groups living with disabilities. It is true that individuals with disabilities are at increased risk of abuse and exploitation (Mansell, Sobsey, & Moskal, 1998; Sobsey, 1994) and need curricula targeting these areas (Ballan, 2012; Gerhardt, 2006; Gordon, 1971; Kempton, 1993; Kreinin, 2001; Mitchell, 2010; Travers & Tincani, 2010). Nonetheless, this kind of discourse used on its own fails to address the sexual rights of the individual and thereby negates a view of the person as a whole (Herr, Gostin, & Hongju Koh, 2003; Kaeser, 1992; Lyden, 2007; Niederbuhl & Morris, 1993; Stavis, 1991).

**Issues of translation.** Another common finding was that individuals with autism have difficulty translating theory into practice (Hatton & Tector, 2010; Hellemans et al., 2007; Konstantareas & Lunsky, 1997; Ruble & Dalrymple, 1993). Thus, although they are able to understand what they are taught in a formal setting, they are less able to apply this information in their daily practice. Surprisingly, this finding also pertained to individuals at the high-functioning end of the spectrum (Hénault et al., 2003; Stokes & Kaur, 2005; Stokes et al., 2007). Thus, increased cognitive ability does not necessarily translate into improved appropriate sociosexual

behavioural skills. Moreover, these deficits persist into adulthood if not addressed in a timely manner (Mehzabin & Stokes, 2011).

Again, defining this deficit as solely internal to the individual with autism may be misguided. As Ballan (2012) pointed out, some parents use fear of inappropriate sexuality praxis as a barrier to broaching the subject with them. Consequently, it is sometimes unclear whether youth demonstrate an inability to translate theory into practice or whether parents or other educators have not provided enough education on relevant topics for youth to be successful. To be sure, the role of the educator is key in ensuring that youth obtain the appropriate learning opportunities. This point is emphasized by a participant in Nichols and Blakely-Smith (2009) who expressed a need for “training for other people to be more understanding, sensitive and appropriate regarding our children’s needs” (p. 80). Addressing youths’ needs, as well as the barriers imposed by others, is necessary if individuals with autism are to be successful at navigating the sociosexual world.

**Considerations of sexuality education.** A prevalent external barrier that can be garnered from the literature is that there is either a lack of appropriate sexuality education for youth with high-functioning autism or that such an appropriate education is not being properly applied. Indeed, only one study has demonstrated effectiveness in increasing meaningful knowledge and skills (Hénault et al., 2003), though the gains were not generalized. A study by Roth (2009) did not obtain as significant an outcome. And although Hénault’s (2006) curriculum is deemed the program of choice for sexuality education for individuals with high-functioning autism, some researchers have cited limitations (e.g., Hatton & Tector, 2010; Roth, 2009).

A cited need in studies by Ousley and Mesibov (1991), Konstantareas and Lunskey (1997), and most recently, Mehzabin and Stokes (2011) and Gilmour et al. (2012), was for

adapted sexuality education to meet the specific learning profiles of individuals with autism. In Hellemans et al. (2007), the formal sexuality education provided was ineffective at producing meaningful change in the population under study. Similarly, parents in Ruble and Dalrymple (1993) confirmed having provided some sexuality education to their children, but this education did not result in positive behavioural changes; whether this was an issue of ineffective curriculum or ineffective teaching is unclear, though both causes were posited. Ineffective educators pose a risk to the provision of sexuality education, as was identified by the lack of confidence of teachers in Kalyva (2010), and has been found elsewhere (e.g., Howard-Barr et al., 2005, Peters, 2007).

Indeed, the question of responsibility is not an unimportant one. Among the few studies that have explored sexuality education for individuals with autism, only Ballan (2012) has openly explored with parents who should be responsible for its provision. Findings demonstrated that most parents see themselves as the providers of sexuality education, though some parents see other professionals (education and health) as playing a shared role. Consistent with this finding, Nichols and Blakeley-Smith (2009) tested a parent-training curriculum, though no data are available on outcomes for children. In the little research that has looked at the efficacy of curriculum provided directly to individuals with autism (Hénault, 2003; Roth, 2009; Tissot, 2009), all programs were implemented by sexuality educators rather than parents. As no research has explored the question of responsibility directly with youth themselves, it remains an area of need.

**Moving forward.** Prior research has demonstrated that individuals with high-functioning autism are sexual and that sexuality is an important dimension in their lives, yet researchers have also demonstrated that they have less sexual experiences than the rest of the population,

indicating that they are more socially marginalized than their neurotypical peers. In short, these individuals require differentiated sexuality education. The literature supports this assertion, but there is a dearth of information regarding what this adapted sexuality education should look like and what its purpose should be. In particular, no research has directly consulted youth with high-functioning autism and their caregivers to understand how they conceptualize sexuality education. Integral to building this definition is an understanding of what sexuality education should be, who should be responsible for its provision, and through what modality. Also, while researchers have identified some of the personal and societal barriers hindering this sexuality education, this picture is incomplete. More importantly, the identification of personal strengths and external supports, in addition to personal and external barriers, can be helpful in providing further depth to the definition of sexuality education in its lived context. Accordingly, this thesis attempts to fill the aforementioned theoretical and applied gaps identified in the research through the methodological and theoretical means described below.

Until recently, research on youth has tended to underrepresent their views. This is due to youth being viewed as the *object* of study, rather than the *subject* or *participant* (Mauthner, 1997). Also for this reason, individuals with disabilities have had their views underrepresented (Swain et al., 2003). It follows that youth with autism have historically been doubly marginalized and were thus even less likely to have their views adequately represented in educational research. This study is concerned with developing a conceptual framework of sexuality education from the emic perspective. To obtain this knowledge, approaches are needed that can compensate for the communicative, behavioural, and social difficulties associated with autism (Mehzabin & Stokes, 2011). Such approaches include more qualitative measures that allow for probing questions, opportunities for elucidation, pauses, and deeper understanding than what has been available

through more traditional and quantitative approaches. This research addresses sexuality education for individuals with high-functioning autism in a novel manner by adopting a socially inclusive framework to examine personal and societal barriers, as well as the individual and social supports that impact the sexuality education received by these youth.

### **Chapter Summary**

In summary, this chapter began with definitions for some key terms related to the discussion. This was followed by a review of the literature on sexuality and autism. In particular, I described research on the perceptions of others toward the sexuality of individuals with autism, self-perceptions, and compared methodologies. I also examined sexuality education intervention research with individuals diagnosed with autism.

Subsequent to this review, I analyzed four main themes that emerged from the literature. This section ended with a discussion of the current gaps in research and possible means of addressing these gaps through my thesis project. Specifically, I identified the need for a conceptual framework of sexuality education, expressed through the voices of youth with high-functioning autism and their caregivers; the identification of needs and strengths held by these youth; as well as societal barriers and supports that hinder or facilitate access to sexuality education. I proposed the use of a socially inclusive framework to support this research. The following chapter provides an in-depth explanation of my proposed socially inclusive theoretical framework.

## CHAPTER 3: THEORETICAL FRAMEWORK

### Introduction

This chapter begins with a brief account of the history and evolution of inclusion, followed by a discussion about some of its current conceptualizations in education and beyond. Next, I provide an overview of paradigms related to disability and situate myself and my research among these various paradigms. Thereafter, an evolutionary theoretical framework-development process is employed to build on preexisting models of disability. With these models as a springboard, I propose a hybrid theoretical framework of social inclusion. Following this, I link the framework to sexuality education, as it relates to youth with autism, and discuss how the framework scaffolds the research questions. The chapter ends with a summary of key points.

### Inclusion: Past and Present

To grasp the current context of inclusion for individuals with autism, it is important to consider how issues related to inclusion and disability have evolved over time. Following this historical overview, I examine the current status of inclusion, particularly from educational and social perspectives.

**Evolution of inclusion.** Individuals with disabilities have had their rights denied or suppressed in the past (Craft, 1994, Di Giulio, 2003; Griffiths, 2003; Monat-Haller, 1992; Niederbuhl & Morris, 1993; Shakespeare, Gillespie-Sells, & Davies, 1996), as evidenced by such practices as segregation, institutionalization, and forced sterilization (Greenspan, 2002; Plaute, Westling, & Cizek, 2002; Radford & Park, 2003; Sobsey, 1994; Watson et al., 2002; Winter, 2003). During the second half of the 20th century, individuals with disabilities in Canada, the United States, and beyond experienced deinstitutionalization and mainstreaming. Prompted by the normalization movement, large-scale institutions were closed (Radford & Park, 2003; Wolfensberger, 1977). Normalization meant improvements in the areas of employment,

legal rights, living arrangements, and self-determination for individuals with disabilities. Its main goal was to *normalize*, or make these areas equal to the standards experienced by the rest of society (Bacharach, 1985; Gardner & Chapman, 1990). Similar in philosophy to the civil rights and feminist movements, normalization appeared at about the same time (Radford & Park, 2003). Inclusion, which evolved from the normalization movement, viewed all persons as full participants in their larger community. This movement recognized the full fundamental rights for individuals with disabilities, including rights related to sexuality. Inclusion is different from normalization in that inclusion means viewing the need for systems to adapt to the individual, rather than the individual needing to adapt to the system. Said another way, “it is not up to the individual to become more ‘normal,’ but rather it is up to the system to be more ‘inclusive’ of all people” (Gougeon, 2010, p. 329). Inclusion is conceptualized primarily in the two spheres of education and society. In the next section, I discuss the implications of defining inclusion in these two contexts.

**Current conceptualizations of inclusion.** *Inclusion* has become a mainstay in educational discourses over the past few decades; nonetheless, the term itself remains highly ambiguous (Fuchs & Fuchs, 1994; Thompkins & Deloney, 1995). An abundance of research on the concept of inclusion in education ranges from studies on the attitudes of teachers toward the inclusive education for students with disabilities (e.g., Avramidis, Bayliss, & Burden, 2000; Horne & Timmons, 2009; Praisner, 2003), to studies specifically about including students with autism (Eldar, Talmor, & Wolf-Zukerman, 2010; Horrocks, White, & Roberts, 2008). In much of this research, the term inclusion is poorly operationalized and its definition is therefore assumed *a priori*. Although a review of this body of work is outside the scope of the current investigation, a discussion about the meaning of inclusion in educational research is pertinent here. Of

particular interest is the answer to the following question: What is the intention of inclusion in an educational setting and beyond? The answer to this question is guided by one's epistemological stance (e.g., Fuchs & Fuchs, 1994; Gartner & Lipsky, 1987; Stainback & Stainback, 1992; Thompkins & Deloney, 1995). How inclusion is theorized impacts the way research is designed and conducted. Research design and process then restrict the kinds of results that can be obtained. These results have implications for policy and further theory development. It is therefore crucial to define inclusion operationally to arrive at a mutual understanding of the term and to guide research that will promote its application.

Most advocates support the education of all students in their neighbourhood school with same-age peers, to the fullest extent possible (Weber & Bennett, 2004; Winter, 2003). However, even this statement means different things to different people. Some believe inclusion should improve academic outcomes for students and eliminate special education (e.g., Stainback & Stainback, 1992). This view of inclusion is commonly referred to as the *full-inclusion* perspective. Such a view has been criticized as denying difference in education rather than eliminating it (Reindal, 2008). Some posit that this criticism is due to the conflict between inclusive discourses in education and the increasing importance placed on standardized testing (Rogers, 2007). Others believe inclusion is less about academic outcomes and more about long-term social inclusion (e.g., Gartner & Lipsky, 1987). This view of inclusion is often referred to as the *social-inclusion* perspective. Proponents of social inclusion argue that a full-inclusion approach can be unrealistic in that it may require too many resources and may not meet student needs (due to the amount of time spent on managing behavioural issues, on highly variable curricular needs, etc.). The former view may seem more inclusive at first because it advocates for the "full inclusion" of the individual, regardless of impairment, whereas the latter view may

promote learning in a separate environment, or learning of different objectives than the standard curriculum. The former full inclusion movement has many advocates, specifically because it is appealing at the philosophical and ethical levels (Thompkins & Deloney, 1995). Arguments against full inclusion may be unpopular and uncommon precisely because they may falsely be associated with rejecting the recognition of the full human rights of individuals with disabilities.

The socially inclusive approach advocates for inclusion that recognizes individual need as well as removing barriers in society to promote individuals' participation in their community in all areas of life, to the fullest extent possible and desired. Indeed, this second view sees the goals of inclusion as threefold: developing social skills, improving attitudes of persons without disabilities toward individuals with disabilities, and promoting positive peer relationships (Gartner & Lipsky, 1987). According to a qualitative meta-analysis of studies on the subject, individuals living with a disability have conceptualized social inclusion as being about valuing (recognizing and accepting) each individual person, engaging in personal relationships with others, having access to appropriate supports, and engaging with the community according each individual's preference (Hall, 2009).

Social inclusion is supportive of practices that have social validity. Social validity is the extent to which interventions (educational or otherwise) are appropriate, acceptable, and produce meaningful outcomes from a social perspective (Cooper, Heron, & Heward, 2007). In other words, practices that are socially valid are deemed to have goals that are socially significant, interventions that are seen as socially acceptable, and having an impact that is socially important for the people themselves (Gresham & Lopez, 1996). According to the Laidlaw Foundation (2002), "social inclusion is about making sure that all children and adults are able to participate as valued, respected and contributing members of society" (p. vii). Moreover, "it calls for a

validation and recognition of diversity as well as recognition of the commonality of lived experiences and the shared aspirations among people” (p. ix). Advocates promote inclusionary practices that will provide the most benefit to individuals in leading full and independent lives as valued members in a community. Needs are gauged according to the long-term benefits for a person, rather than more immediate academic outcomes. For example, improved scores on standardized tests may provide short-term benefits (e.g., academic success, school/school board ranking) but may have limited long-term positive effects for a person’s social inclusion (e.g., limited relevance to daily life or prioritization of certain subjects over others by external stakeholders). A social approach toward inclusion in education is supported by Autism Ontario (2006, 2007), promoting a range of options along an inclusive continuum that suits the individual needs of the student and promotes the outcome of meaningful social inclusion<sup>6</sup>.

Social inclusion has gained increasing recognition and acceptance, from educational theorists to law and policymakers (e.g., Bach, 2004; Herr et al., 2003; Laidlaw Foundation, 2002; Leicester & Cooke, 2002; Nussbaum, 2006, Shakespeare et al., 1996; Tremblay & Pigeon, 2004; Vorhaus, 2005). In 2009, the MEDU established guiding principles in its *Equity and Inclusive Education Strategy*. The document defined equitable and inclusive education as education that “meets individual needs; identifies and eliminates barriers; promotes a sense of belonging; involves a broad community” (p. 11). For its part, the MCYS (2010) adopted social inclusion as part of its overall vision within its *Strategic Framework for 2008–2012*. In addition, the Canadian government recently passed an act for supports and services that promote social inclusion (MCSS, 2008).

---

<sup>6</sup> This approach rests on the foundation of student participation, that exclusion from a regular classroom is not duration-specific, provision of education is predicated on best meeting the needs of students, and that an inclusion plan is the desired outcome (Autism Ontario, 2006).

**Social inclusion and outcomes in high-functioning autism.** Research on adult social outcomes for individuals with high-functioning autism has been limited. Of the research that has been conducted, outcomes have generally been mediocre. In particular, poorer outcomes have been detected in the areas of physical and mental health, relationships, employment, and even mortality rates (e.g., Barnhill, 2007; Howlin, 2000). Overall, studies over the past few decades have revealed that individuals with high-functioning autism tend to not live independently in adulthood, with the vast majority either living with their parents or in a supported residential setting (e.g., Goode, Howlin, & Rutter, 1999; Howlin, Mawhood, & Rutter, 2000; Mawhood, Howlin, & Rutter, 2000; Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989; Tantam, 1991). Also, very low rates of dating and other intimate social experiences, as well as even lower rates of committed relationships, were found in these studies (Goode et al., 1999; Howlin et al., 2000; Mawhood et al., 2000; Szatmari et al., 1989; Tantam, 1991). To illustrate the level of marginalization experienced by some of these individuals, one study indicated that almost half the adult participants in one study had no friends whatsoever (Goode et al., 1999). These findings indicate the need to address the factors that impact the social inclusion of individuals with high-functioning autism.

Among the posited factors that impact the long-term social outcomes of individuals with high-functioning autism have been the social, communicative, and behavioural impairments related to autism, as well as environmental barriers. Research on quality of life, which is closely linked to social inclusion (Renty & Roeyers, 2006), has demonstrated that perceived availability of social supports, and lack of needed formal supports can impact the overall quality of life of individuals with high-functioning autism, including in social inclusion (Renty & Roeyers, 2006). Although some research has linked autism-related impairments to poorer social outcomes in

adulthood (e.g., Howlin, Goode, Hutton, & Rutter, 2004), more research has contested this assertion, with findings demonstrating no meaningful association between the impairments of autism and poorer outcomes (Renty & Roeyes, 2006). Clearly, additional research is needed to identify these barriers (and supports), to understand if, and to what extent, each of these factors plays a role in the social exclusion of individuals with high-functioning autism, and to develop effective means of addressing these factors.

**Social inclusion and the current investigation.** In concordance with the socially inclusive perspective, I believe participation in society to the fullest extent possible is the ultimate outcome of inclusion. Furthermore, I believe that inclusion requires the addition of supports that promote participation, as well as the removal of barriers that prevent the recognition and participation of a person as a full member of society. One facet of inclusion for individuals with autism that continues to lag behind other areas is that of sexuality. Individuals with high-functioning autism have unique needs in the area of sexuality education. In addition, barriers constructed by society continue to persist, preventing access to this education. Addressing needs and barriers to sexuality education can improve the overall social inclusion of these persons. These beliefs impact my research in various ways. To an extent, they affect my epistemological choice and determine the development of my theoretical framework. In these next sections I discuss the ways my views of inclusion impact these aspects of my research.

### **Epistemological Contextualization of Research**

As part of the discussion on the provision of sexuality education for youth with autism, I believe it is important to consider the major paradigms underlying disability. In this area, the positivist paradigm is perhaps the longest standing and most widely accepted (Bach, 2004; Bricout, Porterfield, Tracey, & Howard, 2004; Hegarty, 1985; Mertens & McLaughlin, 2004; Swain, French, & Cameron, 2003). This paradigm favours a quantitative approach, which holds a

singular-reality worldview (Guba & Lincoln, 1998). Examples of positivist paradigms include medical and psychological models. These models focus squarely on the impairment or deficit of the individual and can help to improve outcomes by remediating the deficit through prevention, intervention, or cure. Methods in the positivist paradigm are also immensely useful in increasing knowledge about and measuring or modifying certain behaviours and conditions.

Social constructivists, for their part, view the world as having multiple realities constructed by individuals or groups of individuals (Merriam, 1988; Mertens & McLaughlin, 2004). Thus, meaning and truth are created through interaction (Lincoln & Guba, 1985). According to this view, there is no way to access an objective reality that is independent of people's subjectivities. Rather than remediating problems, qualitative approaches seek to understand how all parts of a phenomenon work together and are thus concerned with the processes that form a complex situation or construct (Merriam, 1988). Qualitative research in education may expose the roles of ideology, organizational dynamics, and social and political processes, as well as offer insights to cultural values in situational practices and interpersonal interactions that occur (Peck & Furman, 1992).

Unlike the medical model, which works at an individual level, and the psychological-behavioural (ABA) model, which sees behaviour as an individual activity, the social model works at what Bricout et al. (2004) identified as the *macro* level, because disability is seen as a construction separate from the individual by institutions, policies, and society. A transactional model addresses the interaction between different individuals and systems. Bricout et al. proposed a transactional model that mediates between the *micro* or individual level and the *macro* or institutional level. This *meso* model, informed by (though distinct from) Bronfenbrenner's ecological-systems model (1992), is concerned with the ways interactions

between youth, family, and different structures (policies, health care, government, school, and society) inform, affect, and are affected by each other. These interactions and relationships are dynamic and can change over time. Although distinct from transactional models, many iterations of the social model incorporate transactional qualities.

Although such distinctions between quantitative and qualitative epistemologies oversimplify the epistemological standpoints held by most researchers, they reflect some of the strengths and limitations inherent in these models. For this project, I sought a theoretical framework that was able to build on the strengths and reconcile the limitations of each paradigm. Certain models have been identified in the literature to address the gaps found in the positivist and constructivist paradigms used on their own. These include transactional and social-relational models (e.g., Bricout et al., 2004; Reindal, 2008). Accordingly, I looked for preexisting frameworks that had adopted a transactional and/or a social approach to issues of disability (particularly autism), inclusion, and education.<sup>7</sup>

### **Evolutionary Development of a Socially Inclusive Theoretical Framework<sup>8</sup>**

Two models were retained and used in the development of my socially inclusive theoretical framework: The *collaborative model for promoting competence and success*

---

<sup>7</sup> Initially, I conceived this research project as being potentially transformative in nature, as it sought to address issues of a historically underrepresented and marginalized population (Mertens, 2007). It also sought to capture the complexity of the issue under investigation, while directly responding to the needs of participant stakeholders in this research (Creswell & Plano Clark, 2011). By adopting a qualitative approach, I aimed at transforming subjects of research into participants in research, allowing them to speak for themselves on a topic that deeply affects all human beings. In this sense, my research sought to limit the further marginalization of the target population of my research (Creswell & Plano Clark, 2011; Mertens, 2007). However, upon consultation with the thesis committee and further study of the literature, it was deemed that this project, although containing minor elements of a transformative approach, was not transformative. Among the lacking elements were participant input in the development of the research problem, research questions, and data-collection tools, as well as limitations in recruitment strategies to allow for youth to participate independent of caregiver consent/assent (Creswell, 2009; Creswell & Plano Clark, 2011; Mertens, 2003).

<sup>8</sup> Portions of this section have been adapted from the previously unpublished document: Gougeon, N. A. (2011). *Personalized service: Practical and theoretical considerations*. Strategic Research Fund Report submitted to the Ontario Ministry of Children and Youth Services.

(COMPASS) and the social-relational model of disability. I now turn to the evolutionary development of the theoretical framework that guides this dissertation, informed by these models.

**COMPASS competence framework.** One promising framework is COMPASS, which was proposed by Ruble and Dalrymple (2002), and more fully articulated by Ruble, Dalrymple, and McGrew (2012). This consultative model adopts a parent–professional collaborative approach for better outcomes specifically for students with autism. The COMPASS

Aims to enhance the competence of not only the student with autism but also the person working with the student by empowering participants (teachers, parents, etc.) through a collaborative problem-solving process that builds on comprehensive, ongoing assessments before decisions are reached . . . it gathers together information in order to reach a consensus for building successful individualized programs. (Ruble & Dalrymple, 2002, p. 77)

It was founded on a transactional framework proposed by Sameroff and Fiese (1990) and a competency-enhancement framework founded on a prevention model offered by August, Anderson, and Bloomquist (1992). Figure 1 shows a conceptualization of this framework. It focuses on the identification of personal (indicated in red) and environmental barriers (indicated in yellow) and supports (indicated in blue) facilitating or preventing the attainment of goals prioritized by the family (Ruble & Mathai, 2010). It highlights the development of competence through interactions between individuals and their environment, and the identification of pathology as within the individual or external to the environment. Thus, this model is both transactional and social. It assesses the current personal and environmental challenges or *risk factors* that inhibit the development of competence, as well as the current supports or protective factors that encourage competence (indicated in green).

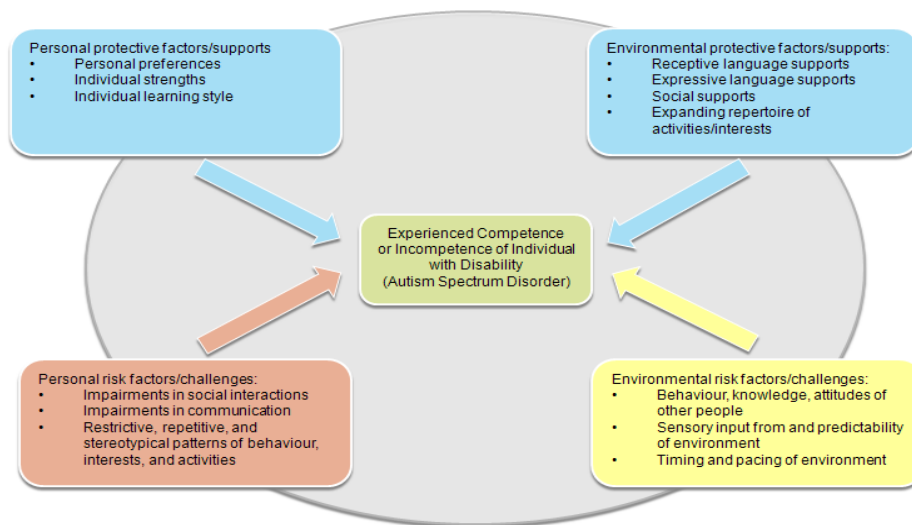


Figure 1. Adapted COMPASS theoretical framework of competence (Ruble & Dalrymple, 2002).

The COMPASS is epistemologically diverse, combining evidence-based and best-practice cognitive, behavioural, developmental, and social-learning interventions to increase the skills of youth and adults interacting with youth (e.g., parents and educators) (Ruble & Dalrymple, 2002). It can be applied across various domains, including sexuality education. It is also one of the first of its kind to have a systematized and tested process. The process involves four-steps, including the identification of personal and environmental challenges, the identification of supports, the identification and prioritization of teaching goals based on team consensus, and the completion of an action plan (Ruble & Dalrymple, 2002). The COMPASS can be used systematically over time to create a feedback loop that is democratic, inclusive, and meaningful to all stakeholders. This approach is the first model of its kind to have been

experimentally evaluated, with documented positive impacts on the development of IEPs and related educational outcomes (Ruble, Dalrymple, & McGrew, 2010; Ruble et al., 2012).

Because of these attributes, the COMPASS is well-aligned with the vision for the current research project. However, it does embody certain limitations. First is the issue of lack of involvement of individuals with autism in the determination of their goals. This issue would be easily resolved if the model were to clearly articulate the centrality of participation by youth themselves to the fullest extent possible. The second limitation is that it was conceived as a model of competence. Unwittingly, this conceptualization engenders a view toward individuals with autism as necessarily being in a state of limited competence because of their autism. In other words, there will always be an underlying pervasive incompetence inherent in an individual with autism. This is not the intention of the framework and is articulated as such by the authors. In fact, they define competence as being a combination of personal and environmental factors (Ruble & Dalrymple, 2002; Ruble et al., 2010, 2012). However, this view differs from the more generally accepted definition of competence as being a set of skills that a person has or lacks. As a result, use of the term (in)competence carries with it meaning that can further marginalize individuals with autism. Another framework that resolves this limitation can be found in Reindal's (2008) model. It is to this framework that I turn next.

**Social-relational disability framework.** Another theoretical structure that attempts to reconcile two seemingly opposing epistemologies is Reindal's (2008) social-relational disability framework. This framework is akin to feminist Thomas' (1999) theoretical framework, which views disability as being about barriers to doing and to being. Reindal, however, applied the framework specifically in the context of education. In this manner it is conceptually similar to the COMPASS. The framework is predicated on previous work by Norwich (2002). It is similar

to Ruble and Dalrymple’s (2002) in that it identifies both biological constraints in the individual (such as the triad of impairments found in people with autism), as well as environmental barriers such as social and societal constructions. Reindal’s model combines the impairment and the environmental barriers to produce disability (see Figure 2). According to Reindal, impairment such as autism only becomes a disability when it is combined with the social and societal barriers that prevent the individual from being fully included. This differs from the COMPASS in that it addresses disability rather than competence. In this sense, the nomenclature adopted in Reindal’s model is better aligned with a socially just approach to research.

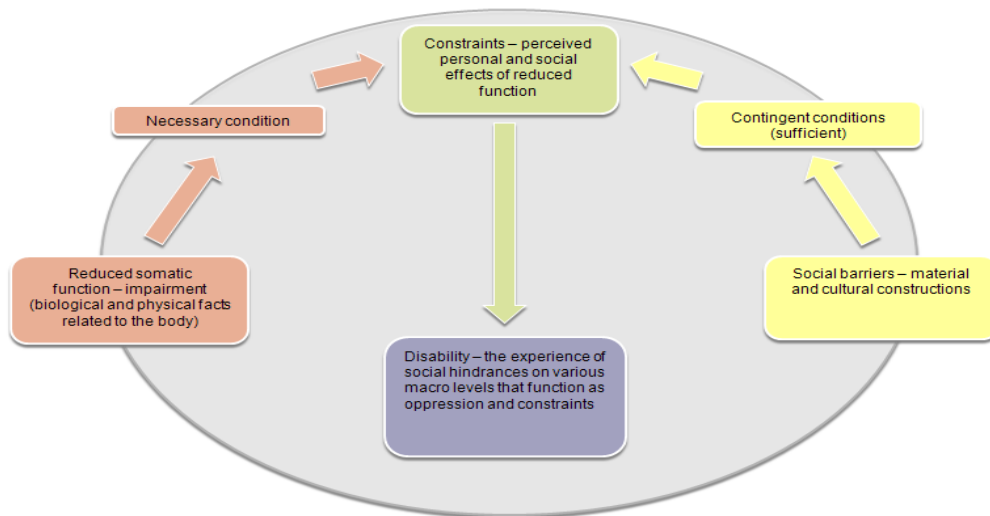


Figure 2. Adapted social-relational theoretical framework of disability (Reindal, 2008).

Reindal’s polarity theoretical framework is a pragmatic means of addressing the personal needs and external barriers experienced by individuals with autism. The first pole is the actual somatic or physical impairment that resides in the individual (indicated in red). This deficit

results in certain limitations and effects perceived by the individual. In the case of autism, the impairments are social, communicative, and behavioural in nature. These impairments are deemed the *necessary* conditions for a disability to exist. The second pole is the experience of external (social/societal) barriers (indicated in yellow). These barriers are the *contingent* conditions that must be in place for an impairment to become a disability. Some examples of societal barriers that exist include negative attitudes toward individuals with autism and systemic discrimination. It is the combination of impairment(s) and social barrier(s) (indicated in green) that results in the experience of disability (indicated in purple). Disability can be seen as a type of oppression or exclusion in the sense that outside factors restrict individuals from participating as full members of a given society (Reindal, 2008; Thomas, 2004). This approach is pragmatic because it reconciles positivist and constructivist paradigms in the following way: it does not divide *additionality* (individual needs acquired through the biological impairment) and *inclusivity* (the removal of social barriers otherwise preventing an individual from full social participation) (Gougeon, 2010; Norwich, 2002; Reindal, 2008).

Some prior research was based on a social-relational framework in education and disability. For example, a study by Connors and Stalker (2007) explored to what extent a social-relational theoretical framework of disability, as conceived by Thomas (1999), adequately describes the experiences of children aged 7–15 who are disabled. Participants included the children themselves, their siblings, and their parents. The research methodology consisted of semistructured interviews, as well as supplemental communication tools and activities that engaged children to better understand how they experienced their disability. Another study founded on Thomas' (1999) social-relational model of disability was that of Worth (2013). Worth's study investigated the experiences of disability and inclusion of visually impaired youth

between the ages of 16 and 25 in separate and mainstream school settings. Worth used various qualitative data-collection strategies, including narrative interviews, life mapping, and audio diaries. The study sought to define inclusion in an educational setting through the voices of youth with disabilities, and in a manner that situates inclusion from social and disability geography perspectives.

Lester (2011) explored how autism was performed as an interactional event among children with a diagnosis of autism, their therapists, and their parents, in a pediatric-therapy setting. The researcher interrogated how participants' everyday discursive practices were shaped and constrained by the institutions that define autism and related plans of treatment. Most recently, Thornton and Underwood (2013) used Reindal's (2008) theoretical framework as the basis for grounded-theory research on child-educator beliefs about disability and inclusion in Ontario. Interview methodology was used to build theory about educator beliefs toward disability and inclusion in a classroom setting.

Like my research project, these studies used qualitative or mixed methods to research various constructs related to disability and inclusion, two of which were directly related to education. Lester's (2011) study is particularly relevant to my area of research because it was based on the creation of definitions of autism, and particularly on the problematics associated with the discourse of medicalizing behaviours associated with autism. Three of the studies privileged the voices of young people in seeking to contextualize, as well as improve the knowledge base and understanding of the topic of investigation. Three of these studies also sought input from adult stakeholders, including two that specifically used caregivers. Although the exact topics of study were different from that in the current investigation, these projects were

similar in scope, type of participants, and methodology. Thus, I retained aspects of a social-relational theoretical framework for my project.

Notwithstanding, the social-relational framework also presented some limitations. Unlike COMPASS, it does not identify personal and environmental factors that would prevent the experience of disability. Further, although it can be used to explicitly identify disability as the consequence of combined impairment with societal barriers, it does not explicitly define the consequence of addressing these barriers. In my view, this provides an incomplete picture of how disability may or may not be experienced. I address this limitation through a social-relational theoretical framework of inclusion.

**Hybrid social-inclusion framework.** From these previous frameworks, which articulate various conceptualizations of competence and disability, a theoretical framework that captured all of the salient aspects of the COMPASS and the social-relational framework of disability was adapted for this investigation (see Figure 3). This framework is a modified and updated version of the social-relational theoretical framework of inclusion proposed by Gougeon (2010) (see also Gougeon & Sénéchal, 2010). This framework takes Reindal's (2008) model one step further by articulating ends of a continuum, where disability is experienced at one end (indicated in green) through the combination of the individual's personal impairment(s) (indicated in red) and external societal barrier(s) (indicated in yellow), and where social inclusion is experienced at the other end of the continuum (indicated in purple) through the acquisition and refinement of adaptive skills to mitigate personal impairment(s) and remove environmental barriers, as well as use of external supports (indicated in blue). In this sense it is like the COMPASS. However, unlike the COMPASS, it does not use the term "competence."

This framework is transactional in that it is founded on the assumption that disability is the interaction between somatic impairment and social/societal barriers. It also recognizes the interaction between the individual, his/her family, and various organizations and systems over time (purple background arrow) and the mutual (though not equal) influences exerted between these actors (Bricout et al., 2004). It recognizes the ongoing and cyclical nature of the phenomenon of inclusion/exclusion. This hybrid framework of social inclusion is recursive in that each concept involved in the experience of inclusion/disability can be seen as one smaller, self-similar iteration of the initial framework; in this sense it is akin to a conceptual fractal (represented by the repeating scheme). For instance, this framework has been used in previous research in the application of personalized services as one of the constructs of social inclusion (Gougeon, 2011).

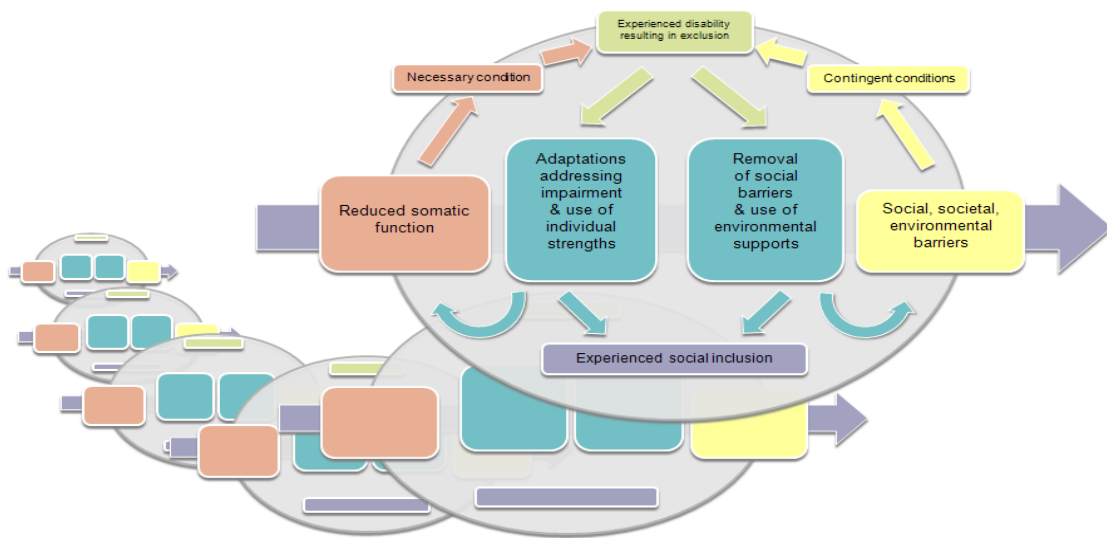


Figure 3. Adapted hybrid socially inclusive theoretical framework (Gougeon, 2011).

The adoption of such an approach allows for a holistic conceptualization of the individual with autism as a member of a community, and thus is a truly socially inclusive model. Such a model

can help identify aspects of disability that are or are not being addressed in a given situation, which can point to specific actionable internal (individual) and external (societal) goals.

### **Sexuality Education in a Framework of Social Inclusion: Current Investigation**

For the purposes of this study, the recursion in application is that of sexuality education. Access to sexuality education, as conceptualized by youth and their caregivers, and as informed by the literature, provides one exemplar of inclusion that itself is part of the bigger framework of social inclusion, and it is in this sense that it is recursive (see Figure 4). Although any number of concepts can combine to make up the overall framework of inclusion, for the purposes of this study I focus on sexuality education. The importance of specialized sexuality education for individuals with high-functioning autism has already been argued in the literature review. So, too, has the importance of identifying the supports and barriers to this education. Equally central to this investigation, though perhaps less obvious, is clarifying the concept of sexuality education in the current context. In this sense, a conceptual framework is needed.

As mentioned previously, ambiguity exists surrounding the concept of sexuality education for individuals with high-functioning autism. Indeed, I ascribe to a pragmatic view of language that sees meaning as something that is ever changing. Concepts are not universal; meanings are created through shared use between people and are therefore context dependent (e.g., Wittgenstein, 1953/1986). These meanings can become variable in and across groups who use them, which can create misunderstandings or apparent conflicts. According to Rodgers (1993),

As a result of conventional use, over time a concept may become ambiguous or vague. Some concepts may seem to be in conflict, and persons who use the concepts may not be able to describe the attribute of the concept of situations appropriate for their application. . . . Through analysis, the researcher can identify a current consensus or “state of the art” regarding the concept, which provides a foundation for further development. (p. 77)

Correspondingly, seeking clarification on the current meaning and use of the construct of sexuality education, as understood by youth with high-functioning autism and their caregivers, and as informed by the literature, can help inform theory and improve the relevance of practice in this area. Allowing for multiple voices and discourses is important on another level.

Disability, as it is understood through a socially inclusive lens, is a social relationship that occurs between various actors (Thomas, 1999). Providing multiple voices in conceptualizing sexuality education allows for disabling interactions to be exposed and understood. This is particularly true with the inclusion of the historically marginalized voices of youth with autism.

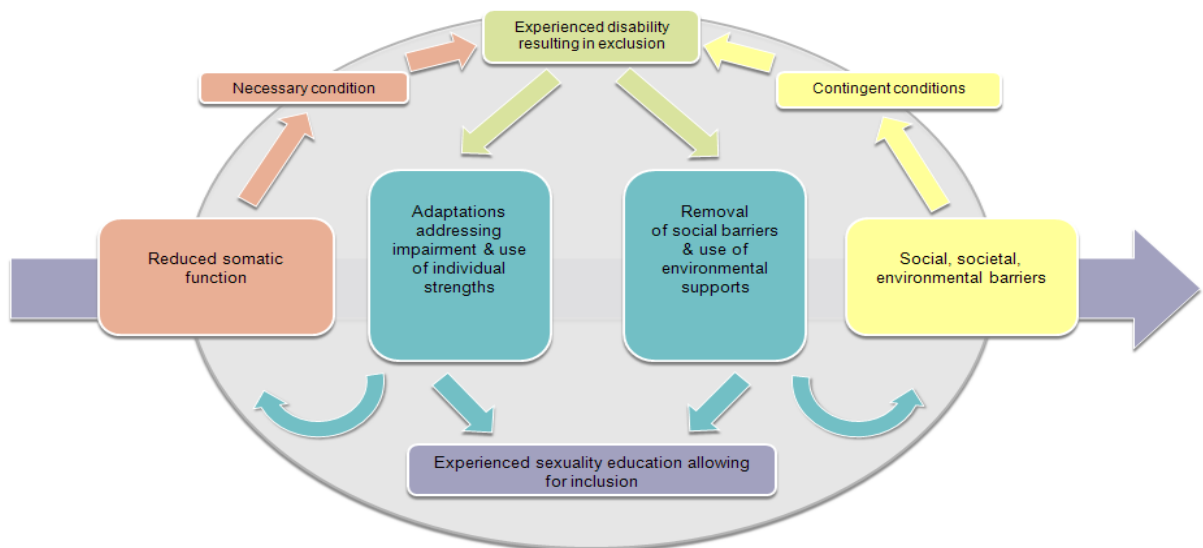


Figure 4. Sexuality Education viewed through hybrid socially inclusive theoretical framework. Adapted from Gougeon (2011).

In deciding how to create a conceptual framework of sexuality education, I relied on my background in ABA. Although operational definitions in ABA are used to define behaviours, the concept of an operational definition translates well to discussions beyond behaviour, including the current context. ABA practitioners define concepts using operational definitions, aiming to use plain, objective, and succinct but complete language. They are usually comprised of both *topographical* and *functional* dimensions. As such, they define something according to what it

looks like (its topography), as well as its outcome (Cooper et al., 2007). In addition to describing what a certain concept is, an operational definition also describes what it is not. Operational definitions based on the principles of ABA fit with a socially inclusive theoretical framework because they are about outcomes. In other words, an operational definition of sexuality education will demonstrate the ways it makes a difference in the lives of individuals through its outcomes of social inclusion (e.g., learning to ask someone out on a date results in going on a date; learning to close the bathroom door before unzipping pants results in not being ridiculed by peers or getting into trouble with authority).

Fittingly, the above principles of an ABA-based operational definition grounded the development of a conceptual framework of sexuality education for this project. However, ABA terminology may not be familiar to many educational stakeholders. For this reason, alternative terms are proposed that reflect the ABA philosophy. One dimension of sexuality is its form. The form of sexuality education reflects the ways it should be provided (its modality) and by whom (its responsibility). In addition to form, the goals of sexuality education is also important. Outcome relates to sexuality education's content (the topics being addressed in the curriculum) and its results. In this study, the outcomes of sexuality education are understood as the increased social inclusion of the individual. Accordingly, the focus of the outcome dimension of sexuality education in the current investigation was primarily on content.

Taken together, the purpose of this investigation was to develop a conceptual framework of sexuality education specific to youth with high-functioning autism, as defined by these youth and their caregivers, and as informed by the literature. In addition, in this project I sought to describe and discuss perceived supports for, and barriers to, sexuality education, as identified by

youth and caregivers. To meet these goals, I developed the following research questions and subquestions:

1. What does sexuality education mean for youth with high-functioning autism and their caregivers?
  - a. What form should sexuality education take according to youth and caregivers?
    - i. Who should be responsible for teaching it?
    - ii. How should it be presented?
  - b. What should be the goals of sexuality education according to youth and caregivers?
    - i. What content should and should not be part of the curriculum?
2. How do prior literature, policy, and curricula in this field inform this definition?
  - a. In what ways is the form of sexuality education similar or different in the literature, policy, and curricula when compared to the form described by youth and caregivers?
  - b. In what ways are the goals of sexuality education different in the literature, policy, and curricula when compared to the goals identified by youth and caregivers?
3. In the context of sexuality education for youth with high-functioning autism, what are the supports and barriers they encounter and what are their impact(s)?
  - a. What are the individual strengths impacting sexuality education?
  - b. What are the social/societal supports impacting sexuality education?
  - c. What are the individual barriers impacting sexuality education?
  - d. What are the social/societal barriers impacting sexuality education?

A visual representation of the concepts and their associated research questions can be found in Appendix C.

### **Chapter Summary**

To recapitulate, this chapter began with a concise historical overview of inclusion. In addition, I discussed some of its current incarnations, including those of full and social inclusion. Subsequent to this, I described paradigms related to disability. Thereafter, I proceeded to illustrate the evolutionary theoretical framework-development process I used to adapt Ruble and Dalrymple's (2002) COMPASS and Reindal's (2008) social-relational models to my own hybrid theoretical framework of social inclusion. Following this, I discussed the framework's application to sexuality education as it relates to youth with high-functioning autism and elaborated on the importance of concept development in this context. The chapter concluded with a full description of the research questions and their connections to the various concepts in the theoretical framework. In the ensuing chapter, I describe the methodology adopted for this study.

## CHAPTER 4: METHODOLOGY

### Introduction

The purpose of this bilingual (English and French) study was to develop a conceptual framework of sexuality education, defined by youth with high-functioning autism and their caregivers, and by the literature. In addition, this study sought to identify the personal and societal supports and barriers that impact sexuality education for these youth. I believe that a clearer conceptualization of sexuality education, as well as its supports and barriers, defined from an emic perspective, will help further develop emerging theory on education in the nontraditional areas of sexuality, as well as inform program, curriculum, and policy development in this and related fields. To meet these goals, using a socially inclusive theoretical lens, the following research questions were elaborated:

1. What does sexuality education mean for youth with high-functioning autism and their caregivers?
2. How do prior literature, policy, and curricula in this field inform this definition?
3. In the context of sexuality education for youth with high-functioning autism, what are the supports and barriers encountered by these youth and what are their impacts?

This chapter reviews the methodology employed for this study, which includes a discussion on the following topics: outline of the research design, participants and recruitment strategies, data sources and data-collection instruments, ethical considerations, data collection and analyses, issues of trustworthiness, as well as limitations of the study.

### Research Design

Due to the emergent nature of the topic and theory, the previously identified limitations of a traditional quantitative self-report methodology used with individuals with autism, as well as the limitations of the sample size, I adopted a qualitative approach for this research. This project

reprinted a modified version of Hutchfield (1999), which itself was an adaptation of the hybrid model of concept development (HMCD) defined by Schwartz-Barcott and Kim (1993) and grounded in Rodgers (1993) which was used in Gougeon (2011). This model, like its precursors, is dispositional and evolutionary, attempting to find meanings through common language and usage, and recognizing changes in these meanings over time. I chose this approach for its evolutionary and cyclical properties, as it allows for a conceptualization of sexuality education to be created that reflects current usage while also incorporating ongoing evaluation and refinement of the concept over time. For example, future research on the subject would further refine the concept proposed in this study in light of its context and usage. In line with the Schwartz-Barcott and Kim (1993) and Hutchfield (1999) models of concept development, a field-work component was integrated in this research project. Data were collected in three separate but overlapping phases, and most of the steps of Hutchfield’s adapted HMCD process were used (see Figure 5).

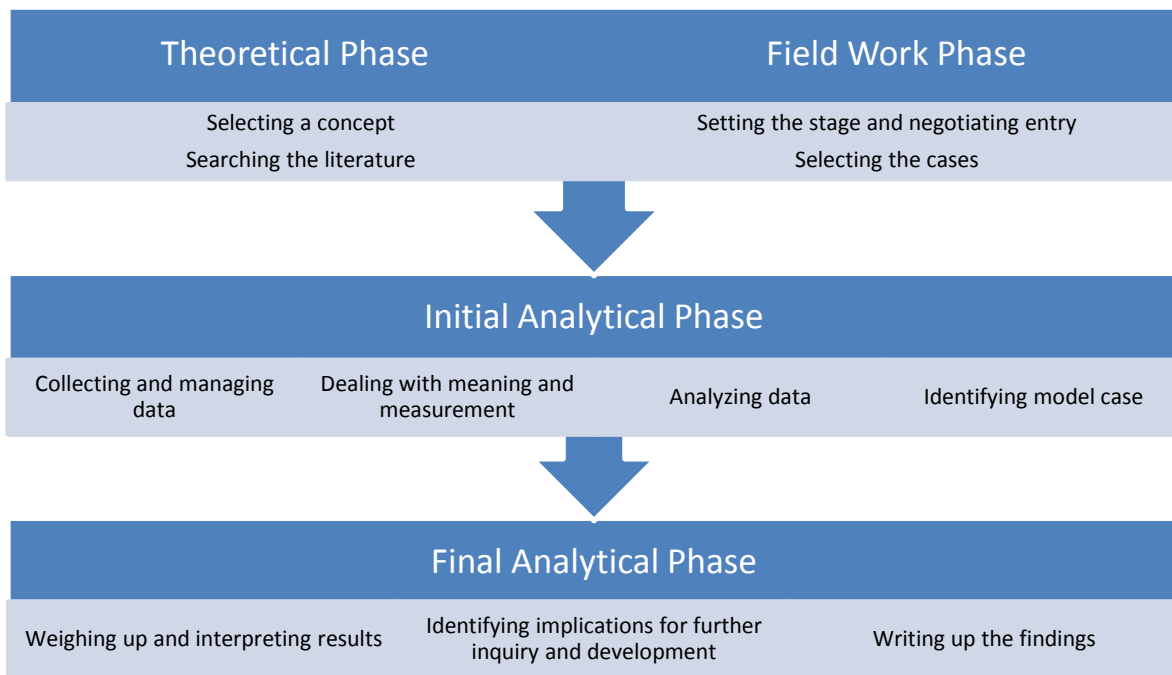


Figure 5. Adapted Hybrid Model of Concept Development (Hutchfield, 1999).

Hutchfield’s model differs from the Schwartz-Barcott and Kim (1993) model by replacing the development of a tentative operational definition with the identification of a model case. For the purposes of my study, however, it was more appropriate to return to and expand on Schwartz-Barcott and Kim’s operational definition, resulting in a conceptual framework. This and other distinctions from the HMCD process that were made in Gougeon (2011) have been repeated here: I used an iterative approach that employed an ongoing and mutually informative literature review and data analysis. In addition, a more descriptive working phase has been included in this framework. Further, a conceptual framework was created as part of the concept-development process. These modifications can be seen in Figure 6.

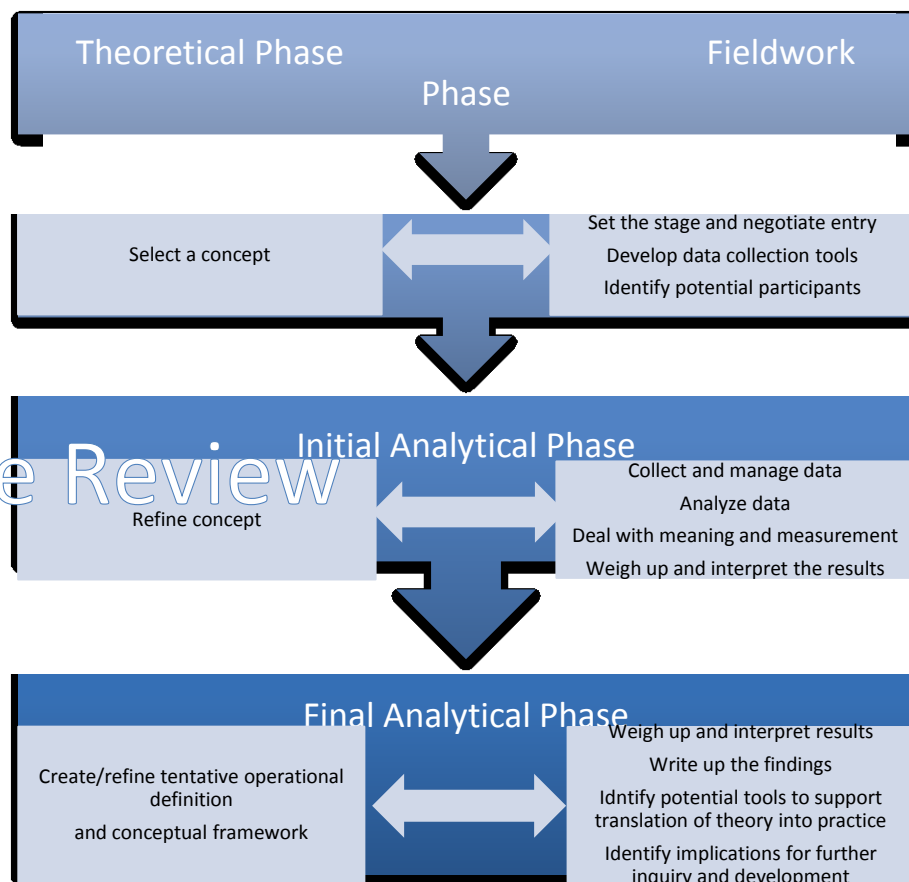


Figure 6. Adapted Hybrid Model of Concept Development. (Gougeon, 2011).

Finally, since this process needs to be repeated over time as the concept under study evolves, a circular arrow has been added to the model to more accurately represent the cyclical process inherent in this model (see Figure 7).

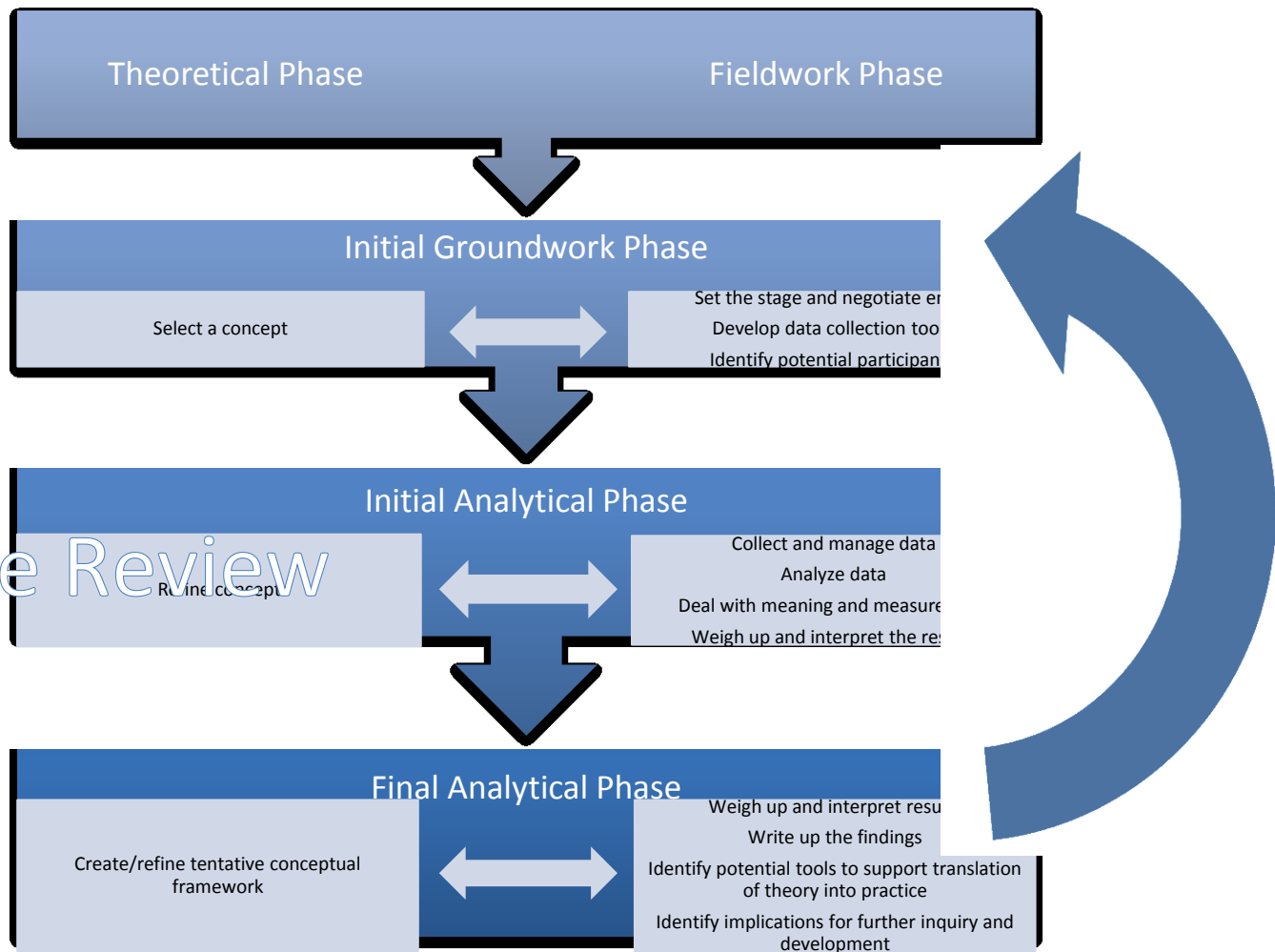


Figure 7. Updated adapted hybrid model of concept development.

The first phase was ongoing throughout the project and involved conducting a literature, policy, and curriculum review. This allowed for identification of initial themes and subthemes used for coding of data obtained from the following phase. The second phase involved collecting and analyzing qualitative and quantitative data obtained from interviews and surveys. Results from this phase were then revisited in light of the literature, policy, and curriculum review.

Information was used to further define, confirm, or negate emerging themes and subthemes. This was an iterative process: the concept development and identification, as well as the exploration of the supports and barriers, were informed by a socially inclusive lens; this theoretical lens was itself informed by the findings obtained from the various data sources.

### **Participants and Recruitment Strategies**

I used a convenience sampling procedure for this project. The criteria for selection of participants for this study are outlined below:

- Youth with high-functioning autism/Asperger syndrome (as reported by their caregivers, established by their official diagnosis and supporting documentation, or as determined by CHEO's Autism Program clinical team) between the ages of 12 and 18 living in Ontario.
- Caregivers of youth with high-functioning autism/Asperger syndrome between the ages of 12 and 18 living in Ontario.

A youth participant age range of 12 to 18 was chosen because it balanced various factors salient to this particular population. For one, the Ontario curriculum begins to address sexuality in earnest in Grades 7 and 8 (MEDU, 1998/2005, 2010a, 2010b). Students in these grades are usually between the ages of 12 and 14, which is the age most children experience changes related to puberty. Further, research has demonstrated that the generally accepted age to begin detailed sexuality education for all stakeholders rests at or around 13 years of age (Cardinal, 1998; Howard, 2001; McKay, Pietrusiak, & Holowaty, 1998; Stone & Ingham, 1998). To mitigate this population's potential disorder-related developmental lag, the age range was extended to 18 years.

Approval to conduct this research was obtained from the University of Ottawa and the Children's Hospital of Eastern Ontario (CHEO) boards of ethics. All data-collection tools were developed in English and French and participants were able to respond in the language of their choice. Youth and caregiver participants were recruited from local, regional, and provincial community autism-resource networks. When applicable, study advertisements were posted on websites, Facebook pages, and Twitter feeds, or were distributed through electronic mailing lists. These advertisements contained information about the research project and my contact information (see Appendices D and E). When possible, I presented at meetings of local associations where I distributed information and participation packages to potential participants.

For families on the waitlist for ABA services through the ABA Services and Supports Program of Eastern Ontario, introductory recruitment letters were sent with information about the research project (see Appendices F and G), a *Consent to Contact Form* (see Appendices H and I), as well as a self-addressed stamped return envelope. Persons who wished to participate in the research project returned a completed contact form indicating their interest in the project.

A total of 15 surveys were returned, 14 of which were usable. Data from these 14 completed surveys, which included six from youth and eight from caregivers, were used to support or qualify the findings. Four surveys were completed by five caregivers recruited through the ABA Services and Supports Program waitlist, as well as four surveys completed by four youth from the waitlist. Four youth survey participants also participated in interviews. Youth survey participants ranged between the ages of 12.5 and 17, with a mean age of 15.1 and median age of 15.5. Five youth were boys and one was a girl. Two of the surveys were completed in French whereas the other four were completed in English. Four caregivers who completed three surveys also participated in interviews. Caregiver survey participants ranged

between the ages of 40 and 50, with a mean age of 43.6 and a median age of 42. One participant was a man, whereas the other seven were women. Four surveys were completed in French and four in English. The survey participation rate was less than anticipated, which restricted the quantitative analyses that could be conducted with them. A summary of survey-participant information is shown in Tables 1 and 2.

Table 1  
*Youth Survey Participant Demographic Information*

Participant	Gender	Age	Language
Youth			
Youth A <sup>ab</sup>	Male	13	French
Youth B <sup>ab</sup>	Male	15	English
Youth C <sup>ab</sup>	Male	17	English
Youth D <sup>a</sup>	Male	16	French
Youth E <sup>b</sup>	Male	17	English
Youth F	Female	12.5	English

<sup>a</sup>Also completed interview; <sup>b</sup>Recruited through ABA Services and Supports Program waitlist.

Table 2  
*Caregiver Survey Participant Demographic Information*

Participant	Caregiver Gender	Age	Language	Child Age	Child Gender
Caregiver					
Caregiver A/B <sup>abc</sup>	Female/Male	41/44	English	13	Male
Caregiver C	Female	45	French	13	Male
Caregiver D	Female	43	French	16	Male
Caregiver E <sup>b</sup>	Female	41	French	13	Male
Caregiver F <sup>b</sup>	Female	50	English	17	Male
Caregiver G <sup>ab</sup>	Female	41	English	15 & 17	Both male
Caregiver H <sup>a</sup>	Female	40	French	16	Male
Caregiver I	Male	49	English	12	Female

<sup>a</sup>Also completed interview; <sup>b</sup>Recruited through ABA Services and Supports Program waitlist; <sup>c</sup>One survey completed by two caregivers—analyzed as one survey.

Eight families participated in the interview portion of the study. A total of 20 persons were interviewed, including nine youth and 11 caregivers. In all, 17 interviews were conducted: nine interviews were conducted with youth and eight interviews with caregivers (three couples chose to be interviewed together). Six of the eight families were from the ABA Services and Supports Program waitlist, including nine caregivers and seven youth. Two of the families were from rural areas, whereas six families were from urban or suburban areas. All nine youth were boys, which reflects the higher rate of high-functioning autism/Asperger syndrome reported in boys compared to girls (4:1–12:1) (Baio, 2012; Whiteley et al., 2010). Youth ages ranged between 13 and 17, with a mean age of 14.4 and median age of 14. Six of the youth were interviewed in English, and three were interviewed in French. Five youth attended public school, whereas the other four attended Catholic school. Two participants were siblings. A total of 6 hours and 11 minutes of youth interviews were recorded and transcribed. The duration of youth

interviews ranged between 24 and 55 minutes, with an average duration of 41 minutes per interview, and a median duration of 44 minutes.

Of the 11 caregivers who participated in interviews, eight were women and three were men. Caregiver ages were not recorded, however one caregiver (a grandparent) appeared significantly older than the others. Nine interviews took place in English; the other two in French. One interview was conducted with an Anglophone and a Francophone parent. The interview was conducted in English, though when the Anglophone caregiver left the room, the interview would switch to French. There was a mix of types of caregivers, including eight parents, two step-parents, and one grandparent. A total of 12 hours and 22 minutes of caregiver interviews were recorded and transcribed. The duration of caregiver interviews ranged between 48 minutes and 2 hours and 41 minutes, with an average duration of 1 hour 33 minutes, and a median duration of 1 hour 24 minutes. A summary of interview participant information is shown in Table 3.

### **Data Sources and Data-Collection Instruments**

Qualitative and quantitative data were collected through interviews, surveys, ongoing literature review, and extant text analysis to answer the research questions (see Appendix J). Qualitative data were collected through semistructured interviews. The literature review included recent theoretical and applied peer-reviewed research on key terms related to sex/sexuality, sexuality education, autism spectrum disorders, and other related terms as they emerged through the research process. The extant text analysis reviewed all relevant documentation, including local, provincial, federal, and international policy documents, memoranda, and relevant news stories. A review of pertinent curricula was also conducted.

Table 3  
*Interview Participant Demographic Information*

Family	Participants (Age)	Gender	Interview Language	Location	School Board
Family A	Youth (15)	Male	French	Suburban	Public
	Parent	Female	French		
Family B <sup>a</sup>	Youth <sup>b</sup> (15)	Male	English	Rural	Catholic
	Youth <sup>b</sup> (17)	Male	English		
	Parent <sup>b</sup>	Female	English		
Family C <sup>a</sup>	Parent	Male	English	Suburban	Public
	Youth <sup>b</sup> (13)	Male	French		
	Parent <sup>bc</sup>	Female	French/English		
Family D <sup>a</sup>	Step-Parent <sup>bc</sup>	Male	English	Urban	Catholic
	Youth (13)	Male	English		
Family E <sup>a</sup>	Parent	Parent	English	Suburban	Public
	Youth (14)	Male	English		
	Step-Parent	Female	English		
Family F	Youth <sup>b</sup> (16)	Male	French	Urban	Public
	Parent <sup>b</sup>	Female	French		
Family G <sup>a</sup>	Youth (14)	Male	English	Rural	Public
	Grandparent	Female	English		
Family H <sup>a</sup>	Youth (13)	Male	English	Suburban	Catholic
	Parent	Female	English		

<sup>a</sup>Recruited through ABA Services and Supports Program waitlist; <sup>b</sup>Also completed survey; <sup>c</sup>One survey completed by two caregivers was analyzed as one survey.

Primarily quantitative data were collected using the following surveys: the *Adapted Parenting and Sexuality Scale* and the *Adapted Youth Sexuality Development Scale – Parent Version* (see Appendices K and L); as well as the *Adapted Youth Sexuality Development Scale – Youth Version* (see Appendices M and N). The first two scales were adapted from the Nichols (2005) *Parenting and Sexuality Scale* and the *Youth Sexuality Development Scale*. The *Parenting and Sexuality Scale* (Nichols, 2005) measures caregivers' attitudes toward their child's sexuality, as well as their knowledge and behaviours to address their child's sociosexuality education. The *Youth Sexuality Development Scale* (Nichols, 2005) was developed to measure parental report of child behaviours, as well as their attitudes and knowledge toward the sexuality of their child with autism. Permission to use these tools for my research was obtained by the author. They have been used in related research, including Roth (2009) and Nichols and Blakeley-Smith (2009). These tools have been recently developed and used with a similar population to those studied in this research project, thereby increasing the face validity and credibility of the data obtained from these tools for this study. The questionnaires were reviewed by a professional with extensive experience in the area of autism, sexuality education, and parent education. The professional's feedback was incorporated into versions of the questionnaires, which were pilot tested. These pilot-tested questionnaires were unaltered. Accordingly, pilot-tested surveys were included in the analysis.

Relevant participant demographic information was collected by questionnaire and interview and used for comparative purposes in the data analysis. Questionnaires included a number of closed-ended questions including Likert-type questions, yes/no/don't know questions, multiple-choice questions, and open-ended/supply questions. Questionnaires were self-

administered using a paper format, and included a consent form (see Appendices K to N) and a self-addressed stamped return envelope to increase response rate.

Because previous research findings have called into question the validity of self-report questionnaires with individuals with autism, two strategies were added to increase the validity of responses. First, in the youth survey, the language was simplified to increase understanding. Also, the option “I do not understand this question” was added to each content question. This was to decrease bias in responses that may have resulted from misinterpretation of questions. Second, a semistructured interview component was added to allow for broader, more comprehensive discussion between the researcher and youth/caregivers. With this strategy I was able to obtain increased information than from surveys alone, as surveys are restricted by their discrete contents. Participants who chose to be interviewed in addition to completing a survey were given a survey at the time of the interview that they could complete at their earliest convenience.

Semistructured interview rubrics for caregivers (see Appendices O and P) and youth (see Appendices Q and R) were used for the qualitative component of this research project. The contents of the interview rubrics used for this project were created specifically for this study’s topic and population; the format of the rubrics was adapted from Gougeon (2011). The language in the youth-interview rubric was simplified to increase understanding. Both youth and caregiver interview rubrics were pilot tested. During the pilot phase, two questions were added to the interview relating to adulthood. Also, following the first caregiver interview, which lasted over an hour, it was determined that 30 minutes was not an adequate amount of time to address all of the questions in a meaningful manner. Accordingly, when contacting the subsequent families, I informed them that the caregiver interview could last an hour or more, depending on the amount

of information families had to share on the topic of discussion. Otherwise, the rubrics were unaltered as pilot tested. The pilot interviews were therefore retained for analysis. The semistructured interview protocols were comprised of predetermined scripts with mainly open-ended questions. Depending on the answers obtained on certain questions, additional probing questions were added or removed. When answers were unclear, participants were prompted for clarification; if answers related to another question in the interview or to the topic generally, the participant was prompted with a follow-up question. The order of the questions varied according to the direction of the conversation during interviews, however, I ensured that all topics were addressed in each interview, as applicable.

### **Ethical Considerations**

All researchers must be concerned with protecting the well-being of participants. This was particularly important in this research project, as it concerned a doubly vulnerable population: youth with autism. In addition, this study centred on the sensitive topic of sexuality education. Care was taken to ensure that participants' rights were protected throughout the research project.

First, the data were collected and managed according to all procedures set forth by CHEO and the University of Ottawa. Except when required by law, all information collected during the study was kept entirely confidential and was stored in a secure place at the offices of the Autism Program of Eastern Ontario. All information collected was password protected and stored on an encrypted USB stick. All computers used for this study were password protected. Only the thesis committee members and I had access to the raw data. Because of the sensitive nature of the topic, a resource list was provided with each questionnaire (see Appendices S and T). This resource list included information about relevant books, curricula, websites, and phone numbers

for local organizations and professionals providing support in the areas of sexuality and sexual health.

Written informed consent was obtained from each participant. The issue of consent is itself a difficult one to negotiate for youth. Historically, youth have been excluded from research because they were considered incapable of consenting on their own behalf. However, this view has evolved into a continuum model of competence. Under this view, children are either viewed as able to consent for themselves, as able to assent for themselves with parent consent, or require full parental consent on their behalf (due to age or developmental stage) (e.g., Fernandez, 2008; 2013; Spriggs, Gillam, Thomson, & Oakley, 2010). This continuum can be problematic for ethics committees and researchers because it does not clearly identify the ages when these stages of competence occur. Moreover, developmental issues can pose problems in determining competence, as may be the case with the youth participants in this research project. As a result, I was required to negotiate some way of determining when consent was to be obtained by the youth alone, and when parental consent was required. The following consent criteria were negotiated with the ethics boards to ensure that youth were protected from undue harm, while also not unnecessarily being excluded from participating in this research project:

- For all youth under 16 years of age, both caregiver and child consent was required for the child's participation in the project.
- For youth 16 years and older, consent was obtained from youth when they were legally able to consent; otherwise, caregiver consent was also required for the child to participate.

Because determinations of competence had to be performed in consultation with caregivers, youth were prevented from opting to participate independently of caregiver involvement and,

arguably, consent, regardless of age. The need to consult with caregivers and possibly obtain consent also prevented use of online-survey methodology. This may have negatively impacted participant rates.

All interviews were conducted in person in youth and caregivers' homes. Prior to beginning the interview, participants were given a copy of the consent form to read (see Appendices O to R). Some youth participants preferred to have the consent form read to them and this was done by either a caregiver or me. Once the consent form was read, I asked participants if they had any questions and answered these questions. Participants were given the right to withdraw from the research project at any point, as well as to choose not to respond to any question for any reason. Participants were also assured of the confidentiality of their information, to the extent permissible by law. Participants then completed two consent forms: one for them to keep and one for me to keep. At this point, permission to record the interview was obtained and recording was started.

To protect individual privacy, interviews were conducted with each stakeholder individually, except in the following situations: caregivers could choose to be interviewed together if there was more than one caregiver present (e.g., a father and a step-mother could be interviewed together); caregivers could choose to have their child present during the interview; youth could have the caregiver(s) present during the interview, if they specifically requested this. A quiet and appropriate location in the home was found and, if necessary, a white-noise machine was offered to increase the privacy of the conversation. It should be noted that of nine youth, six chose to have their caregiver(s) present or in close proximity during the interview.

Although the focus of the research centered primarily on qualitative interviews, and these interviews were conducted with eight family units, the focus of the study did not adopt a multiple

case-study approach. Although epistemologically appropriate, the amount of information associated with each family unit posed a threat to the anonymity and confidentiality of those participants whose information was being reported in each unit. Indeed, if such information was presented in unit form, it could provide a more holistic picture of the way sexuality education was conceptualized at a family level. However, such a representation would force the repersonalization of information shared in that family. This would threaten the privacy and confidentiality of those individuals who chose to be interviewed individually in the family unit. In other words, what was said in confidence by one family member during an interview could possibly be revealed to other family members if findings were reported from a family-unit case-study perspective. Therefore, although I could look at the information in a dyadic unit (caregiver–child) for my interpretations, I had to ensure that the findings were presented in such a way that linkages could not be made between data from various family members. For these reasons, analyses were conducted around analytic categories rather than cases. In addition, to ensure participant confidentiality and anonymity, pseudonyms were employed, but no other related information (e.g., age, pseudonyms of other interview participants) is associated with individual quotations. Although I have made every effort to ensure confidentiality and anonymity of the data, because of the small sample size, it is possible that individual participants will deductively recognize comments made by members of their family.

### **Data Collection and Analyses**

Data were collected in three separate but overlapping phases. Data were triangulated to enhance the validity of the data by quantitatively analyzing information obtained from survey questions, and by qualitatively analyzing information obtained through the ongoing literature review, the extant text analysis, and the semistructured interviews.

An ongoing literature review, detailed in Chapter 2, began in 2007 and continued until 2013. Documents of interest included published research, policy documents, and practical literature in areas related to the research topic. Documents were retained for their relevance to the subject. Promising sources cited in initial documents were consulted and included for analysis. As themes emerged from the data, additional literature was consulted and analyzed according to the research questions/subquestions, and according to categories that matched the concepts in the theoretical framework. As themes evolved throughout the analytic phase of the research, literature was analyzed in light of these evolving themes.

Quantitative data were collected by survey. Surveys were provided in paper format to potential participants and returned by mail using a self-addressed stamped envelope. Data were entered into and analyzed using SPSS (2009) software, thereby minimizing rater error and providing enhanced reliability of results (Colton & Covert, 2007; Fraenkel & Wallen, 2003). Due to the small sample size, the types of analysis that could be conducted were limited and the power of statistical tests was reduced. Frequencies for all variables in the dataset were calculated. Some questions included in the survey were open-ended. Responses to these questions were qualitatively coded using the coding scheme outlined for the interviews. Data that were pertinent to the qualitative findings are discussed in subsequent chapters.

Descriptive statistics were calculated for the Adapted Parenting and Sexuality Scale. This scale was comprised of five subscales measuring the following constructs: acceptance, communication, competence, knowledge, and worry. The overall mean and standard deviation were calculated for each construct subscale and are presented below. The internal consistency of each subscale was assessed using Cronbach's alpha reliability estimation. Internal reliability varied between .74 and .87 for all five scales. Thus, despite the extremely small sample size, the

reliability of the scale items ranged from acceptable to good (DeVellis, 2003; George & Mallery, 2003; Kline, 1999; Nunnally & Bernstein, 1994).

A total of nine youth interviews and eight caregiver interviews (with 11 caregivers) were conducted. All interviews took place in person in the youth and caregivers' homes. Unless specifically requested by youth, each child was interviewed alone and in a private location. Most youth actively requested the presence and participation of their caregivers. For those youth who were interviewed privately, one left the room to consult with a caregiver on multiple occasions, whereas another youth promptly explained to the caregivers what had been discussed following the interview. Thus, of nine youth, only one actually had what could be deemed a private interview. For caregiver interviews, when more than one caregiver consented to participate in the study, only one interview was conducted with both caregivers. However, for purposes of data analysis, both opinions were considered and reported as separate data. In total, three caregiver interviews were conducted with two caregivers present. Generally, youth were not present during caregiver interviews, however in two instances three youth did participate intermittently in caregiver interviews. Interviewees were allowed to skip questions, take breaks, ask that questions be repeated, or stop an interview at any time. Participants were also able to ask questions if something was not clear to them.

Following each interview, I recorded my observations and initial impressions through journaling. I recorded and fully transcribed all interviews. I noted verbal emphases with punctuation and italics. I included nonverbal (e.g., laugh, gestures) and other peripheral elements (e.g., phone ringing, someone at the door) in parentheses. I sent a copy of the interview transcript to each participant for verification and amendment, if needed. The data collection and analysis was an ongoing and reflexive process. I used a combination of preliminary (preset) and emergent

coding (e.g., Miles & Huberman, 1994). I read through transcripts and large passages, initially grouping them according to research question/subquestion and categories that matched the concepts from my theoretical framework. Next, I reread and coded these chunks of information using coloured coding stripes according to themes/subthemes that emerged from responses to each research question. I initially grouped passages deemed important that did not fit in an existing theme into an uncategorized node to be reviewed and potentially included as its own theme. As I reviewed more data from various textual sources and analyzed survey results, I adjusted themes and subthemes, including expanding some themes/subthemes and collapsing others (Marshall & Rossman, 2011; Miles & Huberman, 1994; Patton, 2002).

As new ideas and themes emerged, I documented these impressions in my research journal as well. I actively sought discrepant views and negative cases and attempted to reconcile these views by acknowledging them and/or refining my thematic categories accordingly. Although demographic factors across youth (age, language, school board) and caregivers (language, child(ren)'s school board, gender) varied, I found no relationships that impacted the findings. The thematic coding procedure continued throughout the project and was performed through the use of QSR International's NVivo9 qualitative data-analysis software (2010). I created summary tables for each finding (Bloomberg & Volpe, 2011), and tabulated supporting quotations for each theme. Deidentified data were reviewed by a knowledgeable peer to ensure interrater reliability of the coding process (Miles & Huberman, 1994).

Upon completion of the data collection and analysis, I proposed a total of eight findings. These findings are put forth in Chapters 5 and 6. I interpreted the findings through the socially inclusive theoretical lens proposed in Chapter 3, and used them to answer the research questions set out at the beginning of this study. Throughout this analytic process, I constructed and refined

the sexuality education conceptual framework developed as part of this study. I describe the final results of the analysis and interpretations of the findings in Chapter 7.

### **Issues of Trustworthiness**

For this research project, I adopted the following dimensions of trustworthiness established by Guba and Lincoln (1998): credibility, dependability, confirmability, and transferability. To meet these criteria of trustworthiness, I used a number of strategies suggested by Shenton (2004), outlined below.

As I was the primary instrument of data collection (Patton, 2002), I attempted to establish my credibility by providing relevant information about my background, education, and experience. Triangulation of data sources (youth, caregivers, and literature) and data-collection methods (interviews, questionnaires, and literature and extant texts) helped increase the study's credibility, as well as minimize effects of researcher bias (Gagnon, 2005; Merriam, 1988; Stake, 1995; Yin, 2003). Various other strategies were employed to increase study credibility. At the outset of interviews, participants were informed that there was no right or wrong answer to the questions being asked. When participants cited documents or resources in an interview, I accessed these resources and included them as part of the data that were analyzed (Shenton, 2004). All participants partook voluntarily in the project, and were given opportunities throughout the data-collection process to skip questions or to withdraw from the study, with no consequence whatsoever. I deemed this particularly important because of the vulnerability of the population and the sensitivity of the topic. I sent a written transcript of the interview to each participant for review and comment, as recommended by Lincoln and Guba (1985), Seidman (2006), and Marshall and Rossman (2011). Participants were able to amend or remove statements made during interviews, as well as provide additional information.

Throughout the data analysis, I obtained responses from a cross-section of participants (youth and caregivers) and actively searched for disconfirming or discrepant data (Colton & Covert, 2007; Creswell & Plano Clark, 2011; Fielding, 2004; Fraenkel & Wallen, 2003; Gagnon, 2005; Mertens & McLaughlin, 2004). Another tactic I employed to increase the credibility of the project was to engage in peer-debriefing sessions. For example, peers in the field of autism reviewed the research proposal and provided critical input. In addition, a peer in the field of sociology with expertise in qualitative and quantitative methodologies reviewed the deidentified data and analyses (Miles & Huberman, 1994). The reviewer verified the findings for each research question for consistency, coherence, and completeness.

A full description of the study's context was provided to enhance its transferability. This included situating this study in its historical context through the examination of prior relevant research, policy, and other literature. Throughout the data-collection and analysis process, I recorded my observations and impressions (Marshall & Rossman, 2011; Miles & Huberman, 1994). As new themes emerged, I revisited previously coded data and further refined the coding scheme according to these new themes. I also used these opportunities to question my position as researcher, particularly my subjectivity (Gagnon, 2005; Mertens & McLaughlin, 2004; Stake, 1995). To do this, during the analysis and synthesis of the data, I employed the technique of *bracketing* (also called *epoché*, Moustakas, 1994), whereby I attempted to periodically and temporarily set aside my personal experiences, assumptions, biases, and theoretical stance to process the data as objectively as possible (Creswell & Miller, 2000; Gearing, 2004; Tufford & Newman, 2012). Journaling and engaging with critical peers were among the bracketing techniques I employed for this project (Tufford & Newman, 2012). These strategies worked to improve the credibility and improve the confirmability of the research. A full description of the

study's methodologies helped enhance its dependability and confirmability. A description of the methodologies' limitations and effects also helped support the confirmability of this research.

These combined strategies helped increase the overall trustworthiness of the findings.

### **Limitations**

There are some notable limitations to this research project, some of which are inherent to qualitative approaches in general, whereas others relate specifically to this project. First and foremost was the small sample size for the survey portion of the study. As a result of this small response rate, data from the surveys were used to support the interview portion of the study. This limitation was mitigated by the high number of participants for the interview portion of the study; participation rates were nearly double the minimum requirement for youth (nine) and more than double for caregivers (11). Nonetheless, a small sample size is an often-cited drawback of qualitative research due to its impact on generalizability of the findings (Gagnon; 2005; Merriam, 1988; Yin, 2003). This issue is related to what quantitative methodologists call the external validity the methodology. However, it is not the goal of qualitative research to represent a sample of a population, but rather to expand and generalize theories. Thus, this study aimed to create generalizable theoretical propositions, or *analytic generalizations* (Yin, 2003).

Another commonly cited drawback of qualitative research is lack of replicability. Although replication is not considered an appropriate goal in primarily qualitative research, transferability is (Gagnon, 2005; Guba & Lincoln, 1998; Stake, 1995; Yin, 2003). To achieve transferability, I aimed to provide sufficient detail in my research, or "thick description," to allow the reader to generalize to their own personal lived and read experiences of the subject (Guba & Lincoln, 1998; Mertens & McLaughlin, 2004; Stake, 1995; Yin, 2003). This was possible through triangulation of data-collection tools and sources (Gagnon, 2005; Merriam,

1988; Stake, 1995; Yin, 2003). The variety of data sources and types allowed me to discover or confirm patterns (Stake, 1995).

Qualitative methodologists agree subjectivity is inherent to all research, however most also distinguish between subjectivity and bias, aiming to expose their subjectivities while also aiming to reduce the amount of bias in their work. Nonetheless, biases do occur; Gagnon (2005) pointed out three of the most prevalent. The first is that of « surassimilation » (Gagnon, 2005), which was also cited by Stake (1995) as the problem of “going native.” This bias occurs when the researcher loses sight of critical perception and adopts the views of the participants. As the level of involvement I engaged in with the stakeholders interviewed was not fully immersive, I do not believe this occurred. Nonetheless, I recognize that my position as researcher is not neutral (Gagnon, 2005; Guba & Lincoln, 1998; Mertens & McLaughlin, 2004) and attempted to situate myself in this study’s context by reporting relevant researcher context (see Chapter 1) and epistemological standpoint (see Chapter 3).

The second type of bias, known as « l’illusion holistique », is the overconvergence of events, especially when the researcher (purposely or not) ignores disqualifying proofs. To minimize this type of bias, I obtained responses from a cross-section of participants (youth and caregivers) and actively searched for disconfirming or discrepant data. This process helped increase the credibility of the assertions inferred from the data (Colton & Covert, 2007; Creswell & Plano Clark, 2011; Fielding, 2004; Fraenkel & Wallen, 2003; Gagnon, 2005; Mertens & McLaughlin, 2004).

The third type of bias, « le biais d’élite », occurs when the researcher overestimates the importance of information obtained from more articulate informants, while simultaneously underestimating the value of information obtained from less articulate ones (Gagnon, 2005). This

was a particularly important bias for me to assess and try to avoid with regards to the youth I interviewed, as they were sometimes less articulate as a result of the ways autism impacted their ability to communicate. To minimize this bias, probing questions were asked to clarify ambiguous answers, and youth were allowed extra time to answer questions. As mentioned before, transcripts were provided to all participants, which allowed them to review, revise, and/or add comments in writing, though none chose to do so. In addition to these strategies, I tried to ensure there was an equitable representation of youth and caregiver voices in my findings.

### **Chapter Summary**

In sum, this chapter provided a description of my project's methodology. I used a qualitative approach to explore sexuality education for youth with autism. More specifically, I engaged a HMCD design to create a conceptual framework of sexuality education and identify supports and barriers to this education, as understood by youth with high-functioning autism and their caregivers. This process was underpinned by a socially inclusive theoretical framework.

Data-collection methods adopted for this project included ongoing literature review, extant text analysis, curriculum examination, youth and caregiver surveys, and youth and caregiver interviews. I collected data according to the ethical standards stipulated by CHEO and by the University of Ottawa, and took particular care to ensure informed consent of all participants, privacy, and confidentiality, as well as safeguarding of information. I collected data in three separate but overlapping phases and triangulated them to enhance the validity of the data. I performed triangulation of the data by quantitatively and/or qualitatively analyzing information obtained from all sources. Finally, I used a number of strategies to ensure that the dimensions of credibility, dependability, confirmability, and transferability were met in assessing the trustworthiness of the data. I addressed some limitations of generalizability and replication inherent in qualitative research and my research project. I ended by distinguishing subjectivity

and bias and discussed the three types of bias proposed by Gagnon (2005) that were relevant to my research. In the proceeding chapter I present the findings of this research project.

## CHAPTER 5: INTERVIEW AND SURVEY FINDINGS

### Introduction

The intention of this inquiry was to develop a conceptual framework of sexuality education, defined by youth with high-functioning autism and their caregivers, and informed by the literature. In addition, this investigation sought to explore perceived supports for, and barriers to, sexuality education, as identified by youth and caregivers. A clearer conceptual framework of sexuality education, advanced from an emic perspective, with the identification of its concomitant supports and barriers, could help develop emerging theory on education in the nontraditional areas of sexuality. This framework would inform program, curriculum, and policy development in this and related fields. In this chapter, I present the key findings acquired from youth and caregivers, preceded by an in-depth review of seven of eight findings, and answers to Research Questions 1 and 3. The chapter concludes with a summary of the central points for these seven findings. The subsequent chapter provides an in-depth review of the fourth finding, which informs the first three findings, using extant texts. This finding answers Research Question 2.

**Data sources and analyses.** Data were collected in three separate but overlapping phases: interview, survey, and literature review. First, I conducted a total of 17 in-depth interviews with nine youth and 11 caregivers. I conducted all interviews in person and fully transcribed them. Interview data were managed, coded, and analyzed with the support of QSR International's NVivo9 qualitative data-analysis software (2010). Qualitative data were coded and analyzed according to research questions and concepts mapped to the theoretical framework, then according to themes and subthemes (Marshall & Rossman, 2011; Patton, 2002) that evolved over the course of the study. I compared and grouped themes among all sources of information

and grouped them according to main themes/groups and subthemes/groups (Miles & Huberman, 1994).

Second, survey data obtained from a subset of interview participants, as well as other youth with high-functioning autism and caregivers were used to support the findings obtained through interviews. In all, six youth surveys and eight caregiver surveys were analyzed. Descriptive statistics were calculated for the Adapted Parenting and Sexuality Scale. This scale was comprised of five subscales measuring the following constructs: acceptance, communication, competence, knowledge, and worry.

The acceptance subscale was comprised of six items ( $\alpha = .74$ ), with higher scores reflecting greater caregiver acceptance of the child's sexuality. The following is an example of the items found in this subscale: "I am accepting of my child as a sexual person." The mean score for the acceptance subscale was 3.90 ( $SD = .69$ ), which, on a metric of 1 to 5, shows an above-average level of acceptance toward the child's sexuality. The communication subscale consisted of five items<sup>9</sup> ( $\alpha = .79$ ), with higher scores reflecting better communication. An example of items found in this subscale is, "I am able to communicate effectively with my child about sexuality and puberty." The average score for the communication subscale was 4.15 ( $SD = .78$ ), which, on a metric of 1 to 5, demonstrates that caregivers had a high level of communication about sexuality with their child. The competence subscale was made up of nine items ( $\alpha = .87$ ), with higher scores demonstrating increased competence in providing for the child's sexuality education needs. A sample item from this subscale was, "I have all of the skills I need to address sexuality issues with my child as they arise." The mean score for the competence subscale was 3.64 ( $SD = .81$ ), which, on a metric of 1 to 5, shows that caregivers had a midrange level of competence in addressing sexuality with their child. The knowledge subscale comprised

---

<sup>9</sup> One item was removed to improve internal reliability.

six items ( $\alpha = .83$ ), with higher scores demonstrating more caregiver knowledge about sexuality education. The following is an example of the items used in this subscale: “I have learned what I need to know to help foster my child's sexual development and learning.” The average score for the knowledge subscale was 4.19 ( $SD = .71$ ), which, on a metric of 1 to 5, shows that caregivers had a high level of knowledge relating to sexuality. The worry subscale consisted of six items ( $\alpha = .75$ ), with higher scores demonstrating increased caregiver worry about the child's sexuality. A sample item from this subscale was, “I worry about my child's sexual development.” The mean score for the worry subscale was 3.02 ( $SD = .71$ ), which, on a metric of 1 to 5, indicates caregivers held a midrange amount of worry toward their child's sexuality.

Third, an ongoing literature review was conducted throughout the duration of the study. Information from this review was used to further validate and qualify the findings from other sources, in particular as they applied to findings related to Research Question 1. This review included recent theoretical and applied peer-reviewed research on key terms related to sex/sexuality, sexuality education, autism spectrum disorders, and other related terms as they emerged through the research process. For the extant text analysis, I reviewed all relevant documentation, including local, provincial, federal, and international policy documents, memoranda, and relevant news stories. In addition to these sources of data, as appropriate, I drew from entries in my research journal to better situate and contextualize the findings.

**Data and the theoretical framework.** In this study, I sought to understand the conceptualizations of sexuality education held by youth with high-functioning autism and their caregivers, using a socially inclusive lens. This theoretical framework conceives of disability as the synergistic effects of somatic impairment and social/societal barriers; thus, it is perceived as a form of oppression and exclusion (Thomas, 1999). Social inclusion is conceived of as the

combination of personal strengths, external supports, and the removal of social/societal barriers, which allows participation in the greater community to the fullest personal extent possible and desired. Various dimensions of inclusion make up the overall framework. Understood in the context of this study, sexuality education acts as one iteration of inclusion in practice. Sexuality education, understood through this theoretical framework, results in improved outcomes, conceptualized as increased social inclusion. This framework provides a scaffold onto which the construct of meaningful sexuality education can be built and understood. To accomplish this goal, three research questions were created. Through the first question, I sought to understand the meaning of sexuality education according to youth with high-functioning autism and their caregivers. I proposed the second research question to gain input from extant texts to inform the meanings of sexuality education obtained through the first research question. From the third research question, I sought to discern supports and barriers to sexuality education, as understood by youth and their caregivers. These supports and barriers can be added into the theoretical framework and can further validate the findings obtained from the first two research questions.

Together, the findings obtained in answering these questions can provide deeper understanding of what is deemed important in sexuality education from an emic and etic perspective. In this manner, results will help in building a relevant and timely conceptual framework of sexuality education for youth with high-functioning autism. It also allows inconsistencies to be exposed, understood, and possibly reconciled. A socially inclusive theoretical lens is useful here to guide a refinement of the meanings obtained through various sources by inserting the various elements to see whether these elements work to promote or hinder inclusion.

The remainder of this chapter focuses on presenting the findings obtained from interviews and surveys. The findings for Research Question 3 are discussed in light of the theoretical framework in the current chapter. The subsequent chapter presents the findings obtained from textual sources and maps the overall findings onto the theoretical framework to see which aspects of these findings best fit a socially inclusive model. Following the presentation and initial analysis of these findings, the final chapter of this thesis offers a discussion that synthesizes the central points of these findings and discusses their deeper meanings, again through the mediation of the socially inclusive theoretical framework.

**Findings overview.** Eight major findings emerged from this study. The first three findings centred on the meaning of sexuality education, as conceived by study participants. The fourth finding concentrated on evidence from the literature to support this understanding of sexuality education, whereas the last four findings focused on supports and barriers to accessing sexuality education. Below are statements summarizing each of these eight findings:

**Finding 1.** Regarding form, youth and caregivers agreed on certain dimensions of sexuality education (responsibility, quality of educator, and presentation), and disagreed on others (priority of responsibility, educator qualities, and gender grouping).

**Finding 2.** There was widespread agreement on the content of sexuality education across youth and caregivers, both for contextualized social/sexual rules and behaviours, and for fact-based information. Caregivers emphasized personal safety and normalization of their child(ren)'s sexuality. Youth and caregivers thought that there were no topics that should be excluded from sexuality education; however, most caregivers identified considerations of developmental maturity in topic delivery.

***Finding 3.*** All 11 caregivers defined sexuality education as extending beyond discrete classroom boundaries and requiring prompt, informal education.

***Finding 4.*** Generally, conceptualizations of sexuality education provided by youth and caregivers were well-supported in the literature and curricula. No policies were found that pertained specifically to high-functioning autism and sexuality education; however, broader policies on sexuality education did support their conceptualizations, albeit to a lesser extent.

***Finding 5.*** Regarding individual strengths, youth and caregivers differed in that many youth struggled to identify individual strengths related to sexuality education, whereas all caregivers were able to identify a number of strengths for their child(ren), including intelligence and empathy. Openness was identified as an attribute by most caregivers, but only by one youth.

***Finding 6.*** Youth and caregivers identified caregivers and other trusted adults as supports in accessing sexuality education. Youth and caregivers differed regarding Internet/media; youth identified Internet/media as potential resources, whereas caregivers perceived them as potential barriers.

***Finding 7.*** Overall, caregivers were better able to identify barriers for youth than youth themselves. Primary barriers identified by caregivers and youth were literal thinking, maturity, and sensory issues/anxiety. A barrier identified by youth but not caregivers was that of poor self-image/confidence.

***Finding 8.*** Overall, caregivers were more able to identify external barriers. Youth and caregivers both identified lack of friends/bullying as an obstacle. Caregivers also identified Internet/media, resource inadequacy, and judgment as barriers, whereas youth identified limited access to information as a barrier.

I created tables to show all of the findings, representing major dimensions and supporting sources. In addition, I assigned codes (e.g., R1, EA3) to each of these dimensions (for each table, codes are located to the far left of items) for use as quick references in the discussion section of this dissertation.

In the following section, I discuss seven of the eight findings by drawing primarily on quotations from youth and caregivers. Prior to delving into these findings, some relevant points bear repeating. First, to protect participant confidentiality, I assigned pseudonyms to all interviewees. As mentioned in the previous chapter, ages and other identifying information are not provided with quotations to further protect participant privacy from other members of their family. Inscribed in a socially inclusive perspective, the goal throughout this chapter is to allow youth and caregivers to describe their world in their own words. More and less articulate individual voices are included in the narrative to equitably represent the historically marginalized voices of youth with autism and to avoid « le biais d'élite » (Gagnon, 2005). Illustrative quotations that represent the depth and complexity of the topic under investigation are presented. Where youth and caregivers have been interviewed together, I have only provided the pseudonym(s) of the person specifically being interviewed. This decision helped maintain the confidentiality and anonymity of other quotations used by the same persons in different parts of the thesis. I have chosen to include myself by name in relevant quotations to explicitly demonstrate that my role as researcher was not neutral: I was not an outside and separate observer. Although I did attempt to bracket my beliefs during the analysis and synthesis phases of this study (Creswell & Miller, 2000; Gearing, 2004; Tufford & Newman, 2012), I was an active participant engaged in dialogue with participants during interviews. Thus, I found that using either my initials or the title “researcher” would be incongruent with my goals. In

situations when I spoke as part of a quotation, I refer to myself by name. In addition to the use of illustrative quotations and citations, survey data and research journal entries are woven into the interview data to support or qualify the various findings.

**Research Question 1: *What does sexuality education mean for youth with high-functioning autism and their caregivers?***

In response to the question “What does sexuality education mean for youth with high-functioning autism and their caregivers?” two dimensions were of particular interest for the research. The first was concerned with what form sexuality education should take. The second dimension was concerned with gaining a better understanding of the perceived goals of sexuality education. In this instance, I sought input on what the content of sexuality education should be. Finding 1 addressed the dimension of form of sexuality education, whereas Finding 2 addressed the content aspect. Finding 3 cut across form and content.

**Finding 1: Form.**

*Regarding form, youth and caregivers agreed on certain dimensions of sexuality education (responsibility, quality of educator, and presentation), and disagreed on others (priority of responsibility, educator qualities, and gender grouping).*

Finding 1 was concerned with the dimensions of *who* should be responsible for providing sexuality education, *what* qualities this person should have, and *how* sexuality education should be presented. Responses provided by youth differed somewhat from responses offered by caregivers. Nonetheless, some general similarities were found. A summary of the results obtained for Finding 1 is shown in Table 4 below.

Table 4

*Summary of Dimensions of Sexuality Education Modality According to Youth and Caregivers*

Modality	Youth	Caregivers
<b>Responsibility</b>		
R1: Caregivers	7/9	11/11
R2: School	8/9	11/11
R3: Community partners/professionals	1/9	11/11
<b>Educator Attributes</b>		
EA1: Personal traits	8/9	10/11
EA2: Relevant experience/knowledge	7/9	0/11
EA3: Knowledge of autism profile	—	10/11
EA4: Alignment of goals with family values	0/9	5/11
<b>Provision</b>		
P1: Group only	6/9	0/11
P2: Mix of 1:1 and group	3/9	10/11
P3: Congregated by gender (partly or fully)	0/9	10/11
P4: Mixed gender	6/9	0/11
P5: Congregated by disorder (partly or fully)	—	10/11

**Responsibility.** One aspect related to the form of sexuality education examined as part of this study was responsibility for its provision. There was general consensus between youth and caregivers, along with some minor differences. A vast majority of youth identified school as the primary provider (8/9) along with caregivers (7/9). Along these lines, when asked who should be the primary provider of sexuality education, one youth, Jeremiah, described his view of a shared responsibility by stating that parents should provide sexuality education “to an extent, but not fully.” He explained,

I think parents should be a back-up in case of somebody like me misunderstands it and needs more of an explanation. And if they need to talk to somebody, like their teacher – their health teacher or Home Ec. [Economics] teachers or even the resource teachers,

anything like that should be explained to the most of the detail about it. So the parents don't have to feel kind of alone, like frightened of telling their children about it. . . . It is their duty to teach their children about things. But it isn't their *every* duty for them alone because I also think that parents should get some help, like just have someone to help explain things to the children. . . . They should explain things, but they shouldn't explain *everything*. (Jeremiah)

Another youth also described how he viewed the responsibility of sexuality education as a shared endeavor: "Um, I think it's sort of half way between the parents and members of the family and the school" (Steve). Steve qualified his answer by stating that some youth might prefer discussing sexuality with one caregiver over another. He explained:

Um, as much as possible I think it's best to sort of get it from both parents, but sometimes it helps if it comes more from one parent than the other. Like I know that sometimes I have personality clashes with my dad so I go to my mom. (Steve)

Other youth, while recognizing the value of both school and caregivers, favoured one over the other. For example, when asked who his preferred provider was, one youth had a distinct preference for school and a straightforward reason for this preference. This reason was provided during our conversation on the subject as follows:

Nathalie: Who would you like to teach you about sexuality education?

David: My teacher.

Nathalie: Anyone else?

David: No. . . . The teachers always do the subjects and I'm just OK with it, and I can catch on pretty quickly.

Another youth was unsure whether caregivers or school was the more appropriate provider. His vacillation can be seen in our exchange below:

Nathalie: So if they were to offer sexuality education, would you rather get it at school or at home? From teachers at school or at home from your parents?

Jason: I'm not sure honestly. Both sound like there wouldn't be too much of a difference.

Nathalie: In what way?

Jason: I don't know. . . I don't know. Just, learning from one place is like learning . . . *learning is learning.*

(. . .)

Nathalie: So if you could have anyone teach you, would rather have your teacher at school, your mom, or your dad teach you?

Jason: Teacher or dad. Actually, also, I'm not sure. . . . I'm not sure which one will be the best source. I don't know if my teacher is good enough.

Survey findings indicated that all youth (6/6) had accessed some form of sexuality education. All youth (6/6) felt that the sexuality education they had received had been useful and most (5/6) felt that further education would also be beneficial. Youth cited family members (4/6), school (4/6), and themselves (2/6) as main sources of sexuality education. However, when asked whether they would want to participate in a school or after-school sexuality education program, half of participants (3/6) indicated that they were not interested. During interviews, only one youth (1/9) identified community organizations as appropriate educators for sexuality education. Survey results were consistent with this finding, with only one youth (1/6) indicating community support as having been a source of sexuality education. In addition, most interviewed youth did not perceive their peers as good educators; however some did identify peers as potential resources. This finding was also supported by survey data, with only one youth (1/6) reporting having accessed sexuality education through a peer. This result is further described in the finding related to external supports.

Caregivers, for their part, viewed sexuality education as a shared responsibility across stakeholders (11/11). An overwhelming majority saw themselves as the primary providers of sexuality education for their child(ren) (10/11), with the support of school and/or community organizations. Participants expressed their views on this aspect of sexuality education in the following ways:

I think sexuality education starts with an open dialogue at home. I was lucky, I had a nurse as a mom and I believe she was my model. I believe we have an open dialogue. It's not kinky or weird or any of the other stuff I've heard from other friends that's just like unbelievable. Like, yeah the stork brings babies or whatever. So it starts with an open dialogue at home, um. I know that doesn't happen so to cover that off I think there has to be at least courses at school, so at least kids know. I mean, again, when I was young you could get gonorrhoea or syphilis. That was it. And, I mean, penicillin and off you go. Now, you could die. Like, realistically. Or you could get a disease that could seriously cripple you. I think the health, the [children's hospitals], the healths, the health officer, the schools have a responsibility to teach the kids. And to fill the gap. I mean, if the kids are hearing about it in the home, great, but without, they have to have these gaps filled. So as a society we have to make sure these kids are getting the information. (Ronan)

I mean, I think everybody has a role to play, yeah, but, some parts, the basics - ultimately the parents, I think, need to make sure that your child knows everything. It doesn't always come easily. Like the child is more embarrassed sometimes when it comes from a parent than when it comes from a more neutral party . . . . We all have a role to play, I think. Yeah, absolutely. And I think with the additional supports, which I can see in a program like the [program offered through community partner] group. (Diane)

One couple discussed how caregivers should be primary providers, but that school also played an important role, especially when parents were unable to address sexuality at home:

Sandra: Well the parents, of course. Um, but again, when you have a child with special needs, what's the right time to do it? It's hard to know because their maturity level may not be where the other children are, so it's just tricky. I mean parents usually know more than the teachers, but again that comes into play, when should it be done? So, it's tricky. I don't think there's a right answer.

(. . .)

Nathalie: (To Marc) Do you agree?

Marc: In anything, not just sex: Being polite, being respectful, being everything in life, your parents should be teaching that.

Sandra: But some, some parents don't talk about it.

Marc That's why there's so many problems today, with kids getting in trouble and everything else, is 'cause the parents don't spend the time with them and teach them anything.

Some caregivers mentioned home, school, as well as extended family members. One example of this was provided by Katherine:

Katherine: I don't know, I guess, I think all of it should start in the home, I really do because that's where they are the most, well, not during week days, but, I really think what they see and what they hear from home is the most important. Because what he hears and what he sees, it sticks. It sticks with him.

( . . . )

Nathalie: So you say that it should start in the home. Is there anyone else that should be responsible for it [sexuality education]?

Katherine: Well certainly the school, I mean 'cause that's where they are learning, but they've done an excellent job with it . . . I don't know if there's, I can't think of any other person . . . Well there's uncle X and he's a great guy and you know we often said "OK you talk to uncle X." He's a good guy, he'd take over for us if need be.

One caregiver recognized a role in providing sexuality education to her children, but in addition to this, conceptualized sexuality education as coming from multiple sources, including through the availability of resources accessible to youth in their environment when and how much they needed them.

Denise : Je pense que, pour moi c'est plutôt que les ressources devraient être disponibles un peu partout, pas juste dans le système scolaire, mais aussi, par exemple, comme des services sociaux dans la ville. Soit, un groupe qui s'occupe plus de l'autisme, comme *Autisme Ontario*, et à la maison aussi, je pense que tout le monde - parce qu'on sait pas où sera le jeune ou avec qui il va avoir contact ou (pause) puis des fois l'éducation peut venir des autres aussi, comme d'autres jeunes ou . . .

Nathalie : Est-ce que tu penses que c'est une bonne chose?

Denise : Bien, c'est une bonne chose si le jeune est bien informé. C'est pour ça que, bien, comme disons qu'un jeune n'est plus dans le système scolaire, donc c'est bien qu'il y est des choses comme *Youth Services Bureau* ou tous les autres endroits où les jeunes peuvent recevoir des ressources, des services, avoir des réponses à leurs questions.

According to another caregiver, community partners were part of a trifecta of sexuality education responsibility which worked together to ensure the child's needs were always met:

If you can get a balance inside those three [home, school, community partners] there, they're going to be OK. . . . If you pull supports from all three, you'll probably get pretty close to what's supposed to happen. As opposed to one being left by themselves on their own because the, what the school knows, and what the parent knows and what the teacher knows, each one of them is blind at some point because you see what's going on on a daily basis at home, they see what's going on on a day to day basis in counseling, and

when you look at these three, you'll probably get somewhere close to what it's supposed to be, because everyone has a different look at what that child is doing at different times, in different settings, and you'll get a much better grasp of . . . what actually is going on, as opposed to what you're looking at inside your fishbowl, 'cause you're inside, right? . . . It would be great for all three of them to try and figure out what to do for that to happen. (John)

Although caregivers generally saw themselves as the primary providers with support from school or community partners, survey data indicated that practices may differ slightly from the described ideal provision. All caregivers (8/8) believed their child would *absolutely benefit* from appropriate sexuality education. Caregivers indicated that their child was more likely to have received sexuality through school (7/8) than from them (5/8), and only two (2/8) supplied the response that their child had received sexuality education from a community organization.

As with youth, interviewed caregivers generally perceived peers as potentially good resources rather than good educators. Survey results supported the limited use of peers as educators (2/8). This reluctance to view peers as good educators was generally attributed to the concern that peers may not have or may not share accurate information. This discovery is further discussed in a subsequent finding. Overall, caregivers and youth agreed that caregivers and school should provide sexuality education. Additionally, caregivers recognized the role of community partners in its provision, whereas youth did not.

**Educator attributes.** Although caregivers, school, and community partners were seen as primarily responsible for sexuality education, more important to youth and caregivers were the specific attributes of persons providing this education. A vast majority of caregivers (10/11) and youth (8/9) agreed that personal traits such as trustworthiness were vital. Youth mentioned additional traits such as creativity, respect, and comfort with the subject matter. A majority of youth also mentioned that relevant experience and education were important factors in a

sexuality educator. One youth provided a detailed account of relevant educator qualities that prioritized, among other attributes, creativity:

Zachary : ce serait quelqu'un qui a étudié dans des multitudes de religions, voir, pas les critères, mais les caractéristiques qui ont rapport à l'éducation sexuelle de cette religion. . . . une personne bonne en mathématiques, qui a une très grande connaissance dans les drogues, ses effets, les mises en situations, une personne très très créative, une personne comme que j'ai dit qui a étudié multitude de religions, puis qui sait toutes les termes médicales, pour chaque partie du corps. Ça, je te donne la réponse la plus ferme possible.

(au sujet des habiletés des enseignants à l'école)

Zachary : Oui, parce que tu vois c'était plutôt combiné. Comme les enseignantes ressources, très grande connaissance sur les anti-contraceptifs, les parties du corps humain féminin. Tandis que l'enseignant avait une très grande connaissance sur les parties du corps masculin, sur les drogues. . . . il était très créatif, il faisait beaucoup de recherches, quand il y avait un terme qu'il ne connaissait pas, il allait regarder sur Google, des choses comme ça, donc c'était un très bon mélange.

(au sujet des habiletés de la mère)

Zachary : . . . Elle a une très grande connaissance médicale et symptômes, contraceptifs. . . . Um, comme quelqu'un qui a . . . . une très grande connaissance sur une multitude de, um, sur des, um, beaucoup de sujets.

Nathalie : Alors est-ce que tu dirais que ta mère est une bonne source d'informations?

Zachary : Non, parce qu'elle n'est pas créative.

Nathalie : Et ton père?

Zachary : Non. Connait rien en éducation.

Another youth described educators as:

Des personnes qui savent qu'est-ce que la sexualité. Euhm, ils ont peut-être eu une relation sexuelle et que c'est des personnes, des personnes qui ne font pas de mauvaises choses avec la sexualité, là. Ben c'est ces personnes-là qui devraient enseigner la sexualité. (Daniel)

Visibly, youth placed much importance on the technical skills of the educator and on the rapport that existed between them, home, and school. An excerpt from my discussion with Jeremiah exemplified this:

Jeremiah: I know her [Home Economics teacher] and she knows me. Plus, I find she's very nice as a teacher. Plus I find she teaches – her teaching techniques are very neat. And her courses are very interesting.

Nathalie: Did you receive sexuality education from your parents? Just one, both?

Jeremiah: I find both. I learned most from my mother, but on days whenever I don't get along with her I will go and ask my dad for information, I find I can talk to him better, (to caregiver) no offense. I find me and him get along a lot better, I can talk to him.

Nathalie: Are there certain questions you prefer asking dad or asking mom?

Jeremiah: I ask my mom more the terms because she knows about it because she works in a hospital. But as I said, we don't get along, I'll go ask my dad and if he doesn't know then I'll come back to my mother.

Interestingly, survey findings indicated that caregivers self-identified some of the key attributes elicited by youth, including comfort, competence, and knowledge. Thus, youth felt that attributes relating to knowledge of sexuality, technical information, and other relevant training were essential in determining educator proficiency for sexuality education.

Although youth cared more about educators' knowledge of sexuality and related topics, a majority of caregivers (10/11) emphasized knowledge of autism. One caregiver commented on the importance of knowing the profile of youth with autism:

I think they'd have to have a handle on the profile, yeah. Yes. Because it causes a lot of grief. Some off the hand comment that may be applicable to 80%-75%, that comment can cause an incredible amount of grief. (Ronan)

Along these same lines, Nancy provided the comment that “the problem when you have a sexuality – any kind of group – is you need someone with the knowledge of Asperger's.”

Another caregiver corroborated this view when responding to the question of whether a sexuality educator should be knowledgeable about her child and his profile:

Yeah, I would think so. I think that's a fair statement. I mean obviously they can't address everybody's unique traits to the nth degree, but certainly being aware of that, it would probably impact your methodology of treating too, you know? Whether you do role play or whether you do whatever, like, knowing those things is helpful. (Diane)

The importance of being knowledgeable about autism was also seen as important in helping caregivers provide sexuality education when they may have otherwise been reluctant to do so. On this topic, one caregiver explained:

So, I somehow think that a base level of it, all right, I don't know if they have to get into the specifics of sexuality education to a really deep [level], um, but at least the idea of reproduction and possibly the start of birth control should be at least a jumping off point that I think a school should always have and like I said, children with Asperger's are always at different levels, but if he's going and seeing counselors, it may be best if the counselor says 'No he needs to learn this now and based on my experience, because I see 100 kids and you see one, and based on all the hundreds of kids I'm seeing every year, they're ready and he needs to move forward here'. And a lot of times parents may be a little gun shy to step up and say 'Yeah, you're right, it is time'. And they may need to get that prod to spur their move forward and to get involved. (John)

Besides being well-versed in the profiles of youth with autism, caregivers acknowledged the importance of an educator's ethos of care. Caregivers described how teachers supported their children in topics related to social and sexuality education in a caring manner. Some of their stories are offered below:

Je pense que [enseignant ressource] . . . , y'l'avait bien accompagné [jeune], tu sais, à le guider, à l'encourager là-dedans. Oui, l'enseignant ressource. Pas juste un prof qui dit, 'ben là on apprend ça là' . . . Parce que là, y'a un moment donné [l'enseignant ressource] l'avait comme un peu dirigé là-dedans. J'avais trouvé ça extraordinaire. . . . Il (jeune) trouvait une fille de son goût puis elle revenait souvent dans ce qu'il disait. . . . Ça fait que [l'enseignant ressource] l'avait un peu accompagné là-dedans. Et puis, ce qu'il avait fait c'est qu'il avait acheté un porte-monnaie, puis dans le porte-monnaie y'avait écrit 'Je suis autiste', euh, quelque chose comme 'Je trouve que tu es belle', quelque chose comme ça, puis son numéro de téléphone. Puis là il dit 'Maman, là tu sais j'ai attendu qu'elle soit calme'. Mais je pense que ça, ça voulait dire qu'elle était toute seule'. Soyons clairs (rire). Et puis, là il lui a dit 'Tu ouvriras ça quand tu seras chez toi'. Ce qu'elle a fait. Puis elle n'a pas donné suite, OK? Fait que là [l'enseignant ressource] l'a accompagné aussi là-dedans. 'Bon ben comment est-ce qu'on peut reconnaître que tu intéresses cette fille-là? Toi, tu fais une certaine avance et elle ne répond pas, ça veut dire que, ou bien elle n'est pas prête, ou elle n'est pas intéressée'. Fait que c'est important aussi, tu sais, de l'accompagner tout au long de ça. (Lucie)

Like if there's a problem, his Spec. Ed. [special education] teacher phones me . . . and says 'he's wearing the same pants'. He has a problem changing pants. His tactile sensitivity is so much that it's very difficult to buy him clothes and he's very picky about what he will wear and how he will wear it and it's ridiculous. He has this one pair of pants and he keeps wearing them. . . . They are trying to teach him that other people will

laugh at you if you wear the same clothes. . . . So Mrs X phones me and says ‘OK, this is an awkward conversation I am going to have with you. But [youth] is wearing the same pants all the time and people are laughing at him and I’m trying to teach him!’ (laughs). So what they do is when they have something major like that, then they call me and then I work with [youth] at home. Then when I have a major problem with [youth] at home then I call the school and tell them ‘This is what I’m working on with [youth] and you need to continue it’. . . . If the school and the parents can’t work together, it’s done. (Nancy)

Thus, although both caregivers and youth viewed educator qualities as important dimensions of sexuality education, the specific qualities each group identified varied. Both groups privileged trustworthiness, but although youth identified knowledge and experience about sexuality, caregivers named knowledge and caring about their child with autism as key educator qualities.

**Provision.** With regards to the *how*, all interviewed youth (9/9) believed that sexuality education should be provided in a group setting. Reasons put forth for group delivery were social and educational in nature, as evidenced by Daniel, who stated « En groupe, peut-être qu’on va apprendre plus mieux parce que tout le monde va avoir une différente opinion », as well as Rick who said “Group is probably funner.” A third of the youth interview participants (3/9) qualified their preference by stating that a mix of 1:1 and group delivery would work best for their particular learning styles. Youth drew on their previous learning experiences to describe their preferences, as represented by the following comments:

I do work well with others but there is a time where I do work alone because I just feel like I just need to work alone. But otherwise most of the time I love to work with other people or do stuff with the class. I find kind of a mixture, like a balance. Like back in grade 9 there was more of a crooked balance. . . . Like I found it was just more work instead of like an activity. (Jeremiah)

Um, it depends, because if I’m working with just a circle of friends it works well. But, if it’s too many people if they’re all being loud and rambunctious it sort of stresses me and gets me off track and those are the situations where I just go to work by myself, be it in another part of the classroom or resource [room]. (Steve)

In these instances, youth identified that flexible groupings were important accommodations for them to learn effectively.

An overwhelming majority of caregivers (10/11) also saw a mix of 1:1 and group delivery as the most appropriate teaching approach for their child(ren). Caregivers, like youth, identified approaches they felt suited the learning styles of their child(ren). For example, Sandra identified group delivery for one child and 1:1 for the other, stating “Yes, very much for him. And he, um, yeah, he would [benefit] because of his personality.” Diane said “I would say smaller group, like 8 to 10 would be the maximum.” One couple identified 1:1, as well as small and large groups:

France: He learns well at school. I think in small and big groups. Sometimes, it depends on the teacher, but he succeeds well in a bigger group at school.

John: Don’t forget that his school is small, so the groups are smaller to begin with.

France: About 20 per group.

John: But he learns well in this setting. He likes 1:1. Yeah.

France: A small group. Yeah. But he’s fine in his class. He used to have a 1:1, a teacher’s aide growing up, but after a while he didn’t need her anymore.

Thus, overall, youth and caregivers generally agreed that a combination of 1:1 and group delivery were the appropriate modalities for sexuality education, with flexibility to meet the needs and preferences of youth.

Also related to the *how* of sexuality education provision was the subject of gender groupings. On this point, youth and caregivers held divergent views. None of the youth identified a preference for segregated genders (0/9), whereas a vast majority of the caregivers supported various degrees of gender segregation (10/11). Most youth had an open mind about having mixed-gender sexuality education. As one youth put it: « Moi, ça ne me dérange pas, si c’est un groupe avec des gars ou avec des filles. Oui » (Daniel). Another youth responded similarly to the

question of whether he preferred learning with just boys or with boys and girls together by stating “I don’t mind” (David). Of those youth who had no preference, some were cognizant of potential discomfort in others. Two participants articulated this awareness when they said,

Moi je trouve que les gars et les filles c’est correct, là, c’est juste que s’y en a que ça les dérange, peut-être qu’ils vont vouloir un groupe pour les gars et un autre pour les filles, là. Mais si jamais la plupart des gens, là, ça leur dérange pas d’être dans un groupe avec des gars, ça va être correct . . . Oui. (Daniel)

For me I’m not sure off hand if it would make much of a difference, but I know that others feel uncomfortable if it were just both sexes mixed. And some still might think it was awkward if it was only the one sex. Me, myself, I honestly don’t think it would matter either way. (Steve)

This awareness of others’ potential discomfort, an example of empathy, was a surprising finding because it was at odds with traditional views of autism. A third of young interviewees stated a clear preference for mixed-gender instruction (3/9). One participant stated he preferred boys and girls together “Because you get different opinions. Yeah” (Rick). Another participant enjoyed mixed gender because of the presence of girls. On this topic he stated: “There’s a reason why I wanted a mixed [group]. . . . Well, the other boys other than me are insane. Absolutely insane. . . . In very sexual and very disturbing ways” (Chris).

Unlike youth, an overwhelming majority of caregivers believed sexuality education should be partly or fully segregated by gender (10/11). Most caregivers considered a partly segregated and partly mixed gender grouping approach was best (6/11). Caregivers felt it important to present certain gender-specific topics separately because of associated embarrassment. As one participant put it “I think that that would probably be better for a sexuality group. Like, I think that keeping it gender, like only one gender would be an important point to do, because I think otherwise what you would have is they would be too embarrassed to ask” (Diane). A similar view, pulled from caregivers’ own experiences, was seen in the following exchange:

Nathalie: And when it comes to sexuality education, would he (child) do better in all boys or a mixed group?

( . . . )

John: I think for different points of it . . . you can do both.

France: It can be both.

John: . . . I think that based on their sex, there are certain, certain situations about sex education are really taught better together, and some are going to be better separate because the fact that, um . . . It's just going to be awkward – the girls wouldn't want to talk about sexuality a lot when the boys are present. . . . They're gonna start talking about birth control and their menstrual cycle and the boys are all going to shut down and say I'm not talking about this because I think it makes them uncomfortable.

( . . . )

France: Yes. Yeah, I would think some specifically should be just the guys or just the girls.

John: I think that there are some parts that should be together at some point so there should be some discussion, because you are going to get the boys saying one thing on one side and the girls saying one thing on the other side . . . And they have to learn to understand what the other one may or may not be thinking in that setting. . . . They get in that room and they talk, the boys and the girls . . . like they have to understand actually, to see both sides. . . . And so you separate them here, and then you get them together to discuss the hard topics, as a group.

This view also emphasized the value of mixed-gender groupings for meaningful learning to occur in a safe environment. Other caregivers brought up the value of partly segregated and partly mixed gender provision of sexuality education, illustrated below:

Je trouve que c'est bon de séparer les garçons et les filles pour certaines choses, tels que les garçons et les filles puissent parler plus ouvertement entre eux, mais en même temps justement parfois il faut qu'ils soient capables de parler ensemble et de discuter ensemble. Parfois c'est bon de juste comme laisser les conflits un peu, euh, se présenter comme y vont se présenter pendant des échanges comme ça. Mais, pour avoir des meilleures relations entre amis et possiblement, je pense ça va les aider à développer des meilleures relations amoureuses. . . . C'est plutôt je pense par l'interaction. Comme, c'est pour ça que pour lui (jeune), je pense, quand il parle et il dit que ce serait bien d'avoir les garçons et les filles dans la même place, mais je pense pour lui ce serait un atout par ce que, en autant que, je sais que pour certaines filles et certains garçons ce serait vraiment comme gênant, mais en même temps pour lui, voir les types de discussions, les types d'interactions, ce serait vraiment bénéfique. (Denise)

Other caregivers were more apt to support fully segregated gender groupings. One in particular stated this view despite having received evidence to the contrary from an expert in the field, as can be seen in our exchange below:

Lucie : Selon Isabelle Hénault (experte en sexualité et le syndrome d'Asperger), ça fonctionne bien aussi les groupes mixtes. Alors . . .

Nathalie : Toi, ton opinion?

Lucie : Moi je pense que les garçons vont probablement être plus gênés de parler de certaines choses que les filles et vice versa. . . . J'imagine, en tant que garçon, « Toi ça t'arrives-tu de ressentir ça, » je sais pas moi, « d'avoir une érection en classe? » . . . Je suis pas sûr que si j'étais un garçon puis qu'y'avait une fille à côté de moi que je dirais ça, nécessairement. Alors que je sais que je suis entouré de garçons, fait que y'a des grosses chances que les gars, ça leur est déjà arrivé, tu sais? . . . Puis en tant que fille aussi, je sais pas moi, par rapport à je sais pas trop quoi, les règles . . . je sais pas si j'en parlerais si ouvertement que ça? *Pas sûr.*

Again, the importance of separate gender groupings to avoid embarrassment was evidenced in the above participant's comments. The theme of embarrassment also came up in one caregiver and one youth survey. The caregiver respondent reported that her child « a une très grande gêne par rapport à la nudité et la sexualité » and that « il est réticent à l'idée de suivre un cours de sociosexualité » (caregiver survey participant). One youth respondent commented that, with regards to sexuality education “sometimes it makes me uncomfortable” (youth survey participant). Overall, then, caregivers differed from youth in their views toward gender groupings, opting for more segregated options than youth. Further, although youth and caregivers recognized embarrassment as a potential consequence of mixed-gender groupings, youth largely perceived this embarrassment in others, whereas caregivers identified this embarrassment as in their children and in others.

A final aspect related to the provision of sexuality education that was elicited by caregivers but not by youth was that of congregated delivery for individuals with high-

functioning autism. The opinion that partly or fully separate sexuality education may be beneficial was held by the vast majority of caregivers (10/11). As one participant put it,

I think in that context [separate setting], when we're talking about the nuances and the social appropriateness, I think that that would be a better format. I think that it, I think that if it was in a regular setting, like non-specific setting with just kids his age, I don't think he'd get as much out of it. I think there would be a lot more silliness and goofing around and you know whatever and with less information being able to get through in the end. Uh, I think . . . with peers more or less of his level, the boundaries, I think they'd have more in-depth questions because they're not alone in that boat (laughs). Because I think he might feel a little intimidated to ask questions with his typical peer group uh because they might make fun of him or laugh at him or may be egged to make some jokes. (Diane)

Other caregivers held this position, but viewed it as a compromise in that it could allow for youth to access needed education safe from judgment by others, but that the need to address the societal barrier of judgment by others in what was termed an “inclusive” setting still needed to occur. As one caregiver explained:

He's, you know, not being sexually inappropriate, he just doesn't know any better. There needs to be more of an understanding, like an open forum kids like [youth] can go ask some questions. They are not inhibited, but they don't know what people are saying, so if you're going to have a sex ed. class . . . if you have a separate curriculum that is just a little more honest and you have other kids like that, then I don't have to worry about phone calls from parents who are very upset because they used the word “penis” today. . . The more open you can be with kids like this, then the more chance they have of adapting to society around them. (Nancy)

Similarly, another caregiver expressed a need for both a separate and an inclusive provision of sexuality education for her child:

Je pense que pour les premières fois comme ça [séparé] c'est un avantage pour faire ses premiers vrais ateliers. Donc c'est certain que pour le moment c'est un avantage. Mais, de toujours rester comme ça, c'est pas nécessairement euh, le meilleur. Ça ne sera pas la meilleure façon pour lui de développer ses autres habiletés sociales, etc. (Denise)

Although not present in youth response, a separate setting for sexuality education was viewed by caregivers as an appropriate alternative to regular formal sexuality education. However, for

some, this view was seen as a compromise until more inclusive practices were in place in the school setting.

**Summary.** The first finding looked at the form of sexuality education, as viewed by youth and caregivers. Dimensions of form included sexuality education responsibility and educator attributes (the *who*), as well as modalities of presentation and gender groupings (the *how*). Regarding responsibility, caregivers and youth agreed that caregivers and school should provide sexuality education. Whereas caregivers recognized the role of community partners in its provision, youth did not. Caregivers and youth viewed educator qualities as important dimensions of sexuality education, although the specific qualities each group identified varied to some degree. Youth and caregivers favoured trustworthiness, but although youth enumerated knowledge and experience about sexuality, caregivers itemized knowledge and caring about their child with autism as key educator qualities. The aspects of grouping and gender provision of sexuality education were also discussed. Overall, there was agreement across groups that a combination of 1:1 and group delivery were the appropriate modalities for sexuality education, with flexibility to meet the needs and preferences of youth. Caregivers differed from youth in their views toward gender groupings, with caregivers supportive of more segregated options than youth. Although youth and caregivers both recognized embarrassment as a potential consequence of mixed-gender groupings, in general youth perceived this embarrassment in others, whereas caregivers identified this embarrassment in their child(ren) and others. Finally, a finding present for caregivers but not youth was the view that sexuality education should be partially or fully provided in a congregated setting, based on the child's autism profile. The ensuing outcome, Finding 2, deals with the content of sexuality education.

**Finding 2: Content.**

*There was widespread agreement on the content of sexuality education across youth and caregivers, both for contextualized social/sexual rules and behaviours, and for fact-based information. Caregivers also emphasized personal safety and normalization of their child(ren)'s sexuality. Youth and caregivers thought that there were no topics that should be excluded from sexuality education; however, most caregivers identified considerations of developmental maturity in topic delivery.*

The goals for sexuality education centred on its content and its outcomes, with content being the area of primary focus. Correspondingly, Finding 2 was concerned with what the contents of a sexuality curriculum should and should not be for youth with high-functioning autism. Generally, there was widespread agreement across youth and caregivers regarding the content of sexuality education. A summary of the results obtained for Finding 2 are shown in Table 5.

Table 5  
*Summary of Dimensions of Sexuality Education Content According to Youth and Caregivers*

Content	Youth	Caregivers
C1: Facts	6/9	11/11
C2: Contextualized socio-sexual behaviours/norms	7/9 (rules & timelines)	11/11
C3: Safety	4/9	11/11
C4: Normalization of sexual behaviour	— (implicit in some discussions)	10/11
C5 : Enjoyment	2/9	2/9 (implicit in some discussions)
C6: Delayed timing of content to balance developmental and physical maturity	—	7/11

**Facts and safety.** Youth and caregivers both considered fact-based information an important aspect of the curriculum, though their reasons and interpretations for including this dimension contrasted. Youth focused on facts from a practical perspective, whereas caregivers focused on facts from a safety point of view. For a majority of youth (6/9), technical aspects of sexuality were key components of the curriculum. Many youth described what they felt was most important in a sexuality curriculum using examples from previous experiences on the subject.

This was well illustrated by Zachary in the excerpt below:

La responsabilité, euh, les cas où ce que les mères ont un enfant, des choses comme ça. Ah, il y a aussi l'alcool. Ça c'est en 8e. Comme les choses qui peuvent - pas affecter - mais influencer sur les choix. Les risques. (pause) Y'avait, ah oui, les condoms. Comme 99.9 p. cent de chances que ça ne va pas, comme, péter. Parce que si ça se casse, pis y'a un sperme qui se rend dans le vagin, ben la compagnie peut dire que peut-être t'es le 0.1 p. cent. . . . Choix à faire. . . Ah, on avait aussi appris qu'il y avait un condom pour les femmes. Ça, tous les gars ont été époustouflés! Moi aussi. Ah, je ne savais pas qu'il y en avait pour les femmes. Il y avait aussi, ah ça ça entraînait dans les drogues, mais c'était des anti-contraceptifs, alors y'avait de la crème qui aidait à éliminer les spermatozoïdes. Je ne m'en souviens plus, mais je pense que c'est du liquide qui est du sperme, des spermatozoïdes, fusionnent avec une, quelque chose qui a rapport avec l'ovule. Puis y'avait de la crème qui était majoritairement, comme 99.9 p. cent efficace. . . Tout est à 99.9 p. cent.  
(Zachary)

Youth were often quite articulate about the various facts that interested them about sexuality. In this sense, they experienced some success in “mastering” the content of sexuality education. On this point, one caregiver described how her youth explained some unfamiliar contents of his sexuality homework to her:

But then when it came to the sexual video, the diseases, I said “Oh my, there are some here I don't know” and there were a couple I wasn't sure of, but he explained them all to me. Every one of them. Yeah, he has a good memory. (Katherine)

Associated with their fears for their child(ren)'s sexual outcomes, all caregivers brought up the topics of facts (11/11) and safety (11/11) in one form or another. Related themes included abuse and disease prevention, contraception, and harassment. Sandra mentioned some of these points when she stated “Talking about the health you know, the anatomy. Somewhat towards

some diseases, knowing that they could get diseases and intercourse, what have you, and explaining that.” Other caregivers expressed the importance of safety as an aspect of sexuality education stemming from their fear of abuse, as it related to attributes of the disorder. This was communicated as follows:

I think he needs to be well informed. . . One fear with him is he wants friends very badly. He said so last year with peer groups and that’s part of the disease, or whatever it is, is communication with peers, and he wants friends so badly and he’s having difficulties of course getting friends and maintaining friendships . . . . But I’m really afraid that even starting high school, that he might, somebody might try to make friends with him for negative reasons and he would follow, probably if he was told that they were gonna be friends of theirs. I’m very afraid of that. And I talk to him a lot about sex and, you know, be careful who your friends are and not let them try to talk you into something that you know is not right because he knows right from wrong, there’s no doubt about that, I know that. (Katherine)

One thing I have been concerned with is because he has Asperger’s, because of that fact, is sex education is very important to get it out there and make sure they’re clear with it is because the fact that they are susceptible to sexual abuse . . . there’s [youth], who really wants to do the right thing. . . . He could very easily fall prey to a predator (snaps finger) like that. . . . And someone like that could really take advantage of him really easily and hold his silence indefinitely because of the fact that he doesn’t always grasp the complete picture of right and wrong and he doesn’t have access to know what’s wrong is wrong because he’s never taught any of it and I think that it’s something that has to be discussed when we’re talking about sexuality. (John)

Concern about children’s sexuality was somewhat supported by caregiver survey data.

For the construct of worry about their child’s sexual development, a mean of 3.02 was obtained on a scale of 1 to 5, demonstrating that caregivers held a medium level of concern. Two items from this construct demonstrated particularly high rates of caregiver worry, including the item “I worry that my child will be abused” and “I worry about my child’s sexual development.” For these items, a majority of respondents (6/8) indicated they had significant concerns.

During interviews, caregivers expressed concern about the possibility of their child becoming a parent at a young age or contracting a sexual infection. In these instances, they

emphasized their role as educators to help prevent these situations. One couple conveyed this point keenly:

Nathalie: So, the topic of contraception – would that be important?

France: Yeah, yes, definitely, I guess, I'm not exactly sure how exactly and how much he would know and all the consequences. . . . As much as you don't want your child to be a father or mother at 16.

John: The possibility is there. I mean, just because you don't think he's socially ready, he will be physically ready soon. And he gets in his own situation where, he's physically ready, and someone else decides this is a good boyfriend to go down the road with. . . . If he doesn't know, he doesn't know about it because he was never taught and that would be our fail, I think.

Safety, conceptualized in the myriad ways outlined above, was a key concern of caregivers that flowed from their views that youth required contextualized information. Thus, facts were considered important by youth and caregivers, though conceived somewhat differently by each group. Whereas caregivers focused on safety, youth were more concerned with learning facts and their practical applications. Also, youth found this dimension of sexuality education to be interesting, in addition to being important.

**Behaviours.** Along with facts, behaviours were seen as an important component of a sexuality curriculum. A vast majority of youth elicited the importance of learning specific sociosexual behavioural rules (7/9). Some youth were concerned about the social rules, consequences, and technical aspects of sexuality. In conversation on the topic, Steve explained his view:

Steve: Well technically it would be explaining, well, since I'm in a Catholic school, it would be explaining what officially the Church thinks about it, but also a bit about what it is physically, like, so you are not completely in the dark about that stuff.

Nathalie: What do you mean by “physically what it means?”

Steve: Like the science behind how it technically happens sort of thing. . . . Like, with the sperm entering the uterus sort of thing. And I find in the Catholic school system, they lean more towards what it means for the Church sort of thing. Like I can understand why,

but. . . . For me, I sorta think it's a mix between what it is religiously and morally and what it is technically.

Nathalie: What's more important?

Steve: Probably what it is morally. . . . "Morally" would be just the basic concepts of abstinence until after marriage, not cheating on a girlfriend or wife sort of thing.

Another youth described his concerns about rules and technical aspects in this manner:

Euh, un sujet là comme qu'est-ce qu'il ne faut pas faire avec la sexualité, sinon quelque chose de grave va arriver à nous ou à l'autre personne. Peut-être expliquer comment que ça fonctionne, oui. Dire, peut-être si jamais quelqu'un a eu une relation sexuelle, ben en tout cas. Tout ce que je pense que c'est correct, pour m'intéresser. (Daniel)

Some youth were concerned about knowing right and wrong behaviours so they could act accordingly. Others were most concerned about the social rules of behaving, and wanted specific timelines and guidelines about when and how aspects of sociosexuality should occur. Jeremiah explained his views on timelines:

Nathalie: Now, what do you think should be talked about?

Jeremiah: The rough around age and when you should do this and that. Like have a girlfriend, or say, or have children because honestly they don't really put a boundary on that lately and it's all over the place for ages and people and whether they should have children or not or girlfriends or boyfriends.

Nathalie: You would like that explained to you?

Jeremiah: Well not just to me, to most people honestly. 'Cause some people, like even besides me, think the same thing – that there's not a lot of boundaries. (pause) Like we're taught everything that happens in a relationship and it goes on from there, but we're not really taught basically when it's gonna all happen.

Caregiver: You want guidelines?

Jeremiah: Yeah, or references on when people should expect it. Not just early ages when it's not expected.

Steve echoed a similar need, but rather than timelines, he wanted guidelines on how to initiate relationships:

Steve: Um, probably one that I know I would definitely need to work on, because I probably wouldn't be able to do it now, is just starting that relationship in the first place.

Nathalie: So how you would meet someone?

Steve: So how you would meet someone and how to keep the relationship going sort of thing.

Nathalie: And that would be important for you –

Steve: Yeah, because I don't, I'm pretty sure I don't have the information as of this point.

Therefore, youth expressed the need to learn about social norms and behaviours, including guidelines and timelines.

Youth and caregivers agreed that sexuality education should cover facts and sociosexual behavioural skills. Indeed, all caregivers saw context and social skills as central for their child(ren) (11/11). For caregivers, facts and sociosexual norms were interconnected; the importance of the interplay between facts and the social context could not be overstated. Its centrality in the lives of children was made obvious in these caregivers' statements:

Le relationnel beaucoup beaucoup beaucoup beaucoup. Beaucoup, oui. C'est très important sinon même peut-être plus quasiment. Parce que le physique un moment donné on, on vient qu'avec l'Internet et tout on vient qu'on, que les jeunes le savent là tu sais, le côté technique des choses. Ça fait que c'est justement ce qui leur manque dans la vie puis c'est ce qui manque d'ailleurs à tous les jeunes quand ils vont sur l'Internet. (Lucie)

I think that these kids, information and socialization are different, when they meet somebody and what they are supposed to do and how they should act and getting cues (pause) verbal cues or even, like, they don't really get all of that, so yeah, it should be part of the education too. So, when they can meet a person, and yeah, is the interest there, is the interest not there, how can you tell if someone is interested and all that. . . . But I wonder if a child with autism or Asperger's maybe they don't get what kids the same age, they would see it right away, but maybe they don't, so some kind of education towards relationships. . . (France)

You can know the function of it, but there's a lot more to it. There's chemistry and there's, you know, uh, the love part of it. I know they can love, that's not what I mean, but there's the whole chemistry part that adds into – you know – not just sex, right? So, that's concerning. (Sandra)

As identified above, caregivers expressed concern for their child(ren) inadvertently breaking social conventions. Some caregivers also expressed fear that their child would be

perceived as a sexual offender, due to lacking appropriate behavioural skills to navigate social and sexual situations. This concern was poignantly shared by one couple:

Ronan: The dance before the, you know . . . before the *you know?* (laughs) The dance – the relationship is the dance. It's the building of that rapport on a different level. . . . If he's met a girl he has a crush on in the [social skills] group, this is the place to, to interact and to work on this and to work through that, the feelings of whether she's interested and whether she's not and dealing with it if she's not, or how do you proceed if she is and that whole dance that doesn't seem to come naturally to kids on the spectrum, you know?

Nathalie: Would you think that that's important? The whole social skills-

Ronan: It's huge.

Alina: Yeah.

Ronan: It's huge. It's about 90% of where he gets himself into trouble. You know, it's like . . . at school, he liked a girl. . . . He didn't get that the girl was totally putting him on, and he said to the girl "I just want to talk to you. Do you like me? I like you." You know it was a very simple conversation, but it was the way that girl was probably feeling a little creeped out over this, and he followed her and held the door open for her for the bathroom. Was he being malicious? No. Or aggressive? He just couldn't get why she wasn't giving him the answer he needed. So, she was very uncomfortable. (. . .) So these are the areas, it is hugely important, these relationships, that he learn the ground rules . . . about relationships, both male and female – like, sexual and non-sexual. Like, what will friends tolerate? When do you cross that line? How do you cross that line? You know, I think most neurotypical people do have a better sense of, you know, things just not to do. Things you don't do or you know it's gonna hurt the friendship or relationship.

Survey results generally confirmed that youth were knowledgeable about privacy rules (e.g., taking clothes off in a private location, knocking on the door before entering a room), though overall, caregivers reported lower rates of privacy behaviours than youth. However, sociosexual normative behaviours appeared to be more problematic for youth. For example, a third of youth (2/6) reported having gotten in trouble (*sometimes* or *always*) for acting inappropriately toward someone they found attractive. The same proportion of youth (2/6) reported having developed a sexual obsession *sometimes* or *often*. A similar proportion of caregivers (3/8) also reported that youth either *sometimes* or *always* acted in socially inappropriate ways toward a person of romantic interest. The same number of caregivers (3/8)

reported that youth had *sometimes* or *often* developed sexual obsessions. One caregiver described her child's inappropriate behaviour as follows: “‘Almost stalking behavior.’ Constant text and phone contact” (caregiver survey participant). Hence, youth and caregivers widely held the belief that sociosexual behavioural rules were a key component of a sexuality curriculum, with caregivers sharing concerns about outcomes in adulthood. These rules included social tenets and consequences, technical aspects of sexuality, and relationship guidelines and timelines.

**Pleasure and normalization.** Two related dimensions of sexuality education elicited in some of the interviews were those of enjoyment of sexuality and the normalization of the sexuality of individuals with autism. Enjoyment was a theme that was less common, being explicitly evoked by only two youth (2/9) during interviews. According to Rick, topics of interest included various positions and the Kama Sutra. In his words:

Rick: I don't know. I don't know. (laughs) Certain positions, and how well to do it. Kama Sutra, um . . . I don't know, I'm joking, I really don't know.

Nathalie: So that is *not* information you want?

Rick: Not for my parents to teach me! That would be sort of awkward!

Nathalie: How about from someone else, like a nurse?

Rick: A friend or a nurse.

The topic of pleasure was also raised by Daniel:

Pour moi l'éducation à la sexualité c'est que, euh, faut que je commence euh, comprendre c'est quoi le corps humain pour moi, là, et comment c'est suivi et pourquoi les gens ont du plaisir à faire euh, à faire des relations sexuelles et comment ce qui, et qu'est-ce qui peut être mauvais avec ça si on l'utilise mal, ouais c'est ça, comme dire qu'est-ce qui est correct avec ça et qu'est-ce qui n'est pas correct quand ils le font, quand on le fait de la mauvaise manière. C'est ce que je pense . . . (Daniel)

Regarding pleasure, most caregivers did not explicitly raise the topic (2/11), however it was implicitly discussed in conversation about other subjects. Hence, pleasure was a less common but noteworthy topic raised during some interviews with youth and caregivers.

A related aspect of sexuality education content evoked by an overwhelming majority of caregivers (10/11) was that of the normalization of their child(ren)'s sexuality. This facet of sexuality education emerged from their safety concerns and the perceived need to recognize the various dimensions of sexuality for youth, not just the problematic ones. They also recognized the importance of supporting youth in a healthy sexual development. Following are some of the ways participants expressed this feature of sexuality education:

The development, the body changing, and his response to feeling that. Like I know some girls have their period for the first time and they have no clue what it is and they think they are dying. It's not everybody's view that's your duty actually doing that. So you could let them know how you are going to develop and what will happen to your body. (Alina)

I've had one conversation with him about . . . what happens when you're sleeping sometimes [nocturnal emissions] (laughs). . . . I think we were having a little bit of a problem with it, so I noticed it was there and I told him it was natural when it happens . . . (Diane)

If you're having erections, masturbation is not far behind. And when that happens, well most of us think that you're the only person in the world that's doing this. And you think what a horrible person you must be. And I think I finally found out at 18 that I wasn't the only one. And I hate to think he would live his life like that – nobody told him - that it's a part of life, you know? *Just don't do it at the table.* (laughs) (John)

In this sense, caregivers wanted to ensure that sexuality education was addressing areas that may cause confusion, fear, or anxiety in a positive and healthy manner. Said another way, caregivers were accepting of their child(ren)'s sexuality and wanted others to be accepting of it as well.

Acceptance was supported in survey results as well. The construct of caregiver acceptance obtained a mean of 3.90 on a scale of 1 to 5, indicating that caregivers were generally accepting of their child's sexuality. An interview participant summed up this view aptly with his comment "Masturbation is normal. It's not something that is abnormal. You're not weird for having these thoughts and having these new desires" (Ronan). This particular view was strongly supported by the survey findings as well. In response to the item "I feel it is acceptable and natural for my

child to masturbate” taken from the acceptance subscale, the vast majority of survey respondents (7/8) felt that this was a *very true* statement.

Although youth did not expressly identify normalization of their sexuality, they did discuss aspirations about their sociosexual future that transmitted a sense of normalization. In other words, youth generally expressed a desire for sociosexual outcomes that were aligned with their neurotypical peers. For example, being in a committed romantic relationship was seen as either a definite or a possible part of their adult vision of themselves. All of them explained that such a relationship was something they would want to pursue when they were older. This vision was described by some of the participants in the following ways:

Je ne pense pas tout de suite être avec quelqu’un, je pense que d’abord si je pouvais, d’abord progresser les choses avant, comme peut-être avoir ma propre maison et mon propre emploi, euh, et puis après je vais commencer à vivre ma vie avec les factures. Et après, je pense que je pourrais être avec moi, j’irais peut-être voir pour trouver quelqu’un qui voudrait être avec moi, là. Et apprendre à se bien connaître avant de faire n’importe quoi par ce que sinon ça pourrait avoir des mauvaises relations et ça pourrait être le divorce, comme c’est arrivé deux fois à mes parents. Donc oui. C’est comme ça que je me vois être adulte, c’est quand je vais apprendre à vivre ma vie moi-même. (Daniel)

Ben, je vais trouver une job. Je vais me marier. Après, continuer de faire la job, avoir des enfants si j’en ai. Travailler pour les enfants. . . . Oui je veux au futur me marier, mais je dois commencer avec une blonde. Un « bf » et une « gf » - un petit mot pour boyfriend et girlfriend. (Justin)

Likewise, all caregivers saw a future for their children that included the possibility of being in a committed romantic relationship. Caregiver survey results corroborated this finding, as was particularly evident in the majority positive response to the item “I want my child to have a sexual relationship when they are ready and if they choose to” (7/8 indicated this statement was *mostly to very true*). Some caregivers were quite clear and positive on this point; as one caregiver stated: “I want my son to have a life . . . I want him to have a girlfriend” (Nancy). Similarly, some caregivers expressed hope in their outlooks about their children’s future, as seen in the following example:

C'est certain que je lui souhaite d'avoir plus d'amis, puis de faire plus de choses, plus souvent, de façon indépendante avec ses amis puis de trouver quelqu'un, d'avoir une relation amoureuse aussi. (Denise)

Some expressed more uncertainty regarding whether such a relationship would materialize or how their child would cope with relationship woes, but still conveyed a sense of hope regarding the development of their child's social and sexual identities:

I certainly hope [for a relationship] for him, yeah. I fear that if he got involved and it doesn't work out that the reaction, that would be a fear for me. It would be like catastrophic to him. So if he really liked a girl and he went out and then she broke up with him, it would be like the world ended, you know? (laughs) That would be a fear for me, it would be the negative side of the break-ups and that kind of thing. (Diane)

Relationships. I just don't know if he understands enough how – he empathizes with people – which often they have trouble with. But he does, he does know, I just don't know if he's going to be able to interact with another female, you know, a partner and know that he's doing . . . understanding that he's doing something wrong, per se. You know when it comes to relationships? And he won't understand why the other person's upset, that kind of thing, and that all goes into that. So, it's worrisome. . . Someday I wonder how he's going to have a partner. . . I hope so. (Sandra)

In summary, pleasure was a less common, but nonetheless important topic that was raised either explicitly or implicitly by youth and caregivers. Enjoyment was inadvertently linked to the content area of normalization of the social and sexual identities of individuals with high-functioning autism. For caregivers, supporting their child(ren)'s healthy sexual development was a key consideration. Important for youth and caregivers was the shared view of sociosexual outcomes that were more similar to those of the rest of society than different.

**Excluded topics.** The previous section addressed what sexuality education should be about, whereas this section looks at what sexuality education should not be about, according to youth and caregivers. An overwhelming number of youth (8/9) and caregivers (9/11) did not perceive any topics as disallowed. Youth were generally very precise on this topic. Zachary, for example, stated « C'est tous des sujets abordables. » Another participant responded to the question of whether there are any topics that should not be included as part of sexuality with:

“I’m OK with it” (Rick). To the same question, yet another youth stated: “No, not that I can think of. Nothing is coming to me” (Jason).

Some participants felt that all topics needed to be covered for their own safety. Jeremiah explained his safety-related view in this manner: “At this point, from what I learned, the subjects we were taught I think basically are necessary. Because even about learning the abuse I think that’s necessary to learn because people can abuse relationships.” David, for his part, held the view that all topics were important for safety reasons as well. He stated: “They’re trying to make us more prepared. . . . ’Cause we’re the next generation. They’re trying to protect us.” One youth did not deem any topics as inappropriate, but was mindful that others might hold different views. In response to the question of whether there were any topics that should be avoided, he stated:

Qui devraient pas être abordés? Non, mais si il y a certaines personnes qui vont se sentir un peu gênées de l’aborder, ce serait peut-être plutôt de, on devrait peut-être d’abord montrer les grilles avant de parler de ceci, je pense. Comme peut-être quand les personnes parlent de sexualité on se sent gêné là, mais moi j’avais commencé avec des feuilles, des grilles, avec des images. Je pense que comme ça ça m’a fait pas gêner du tout, ça m’a fait plutôt comme comprendre. (Daniel)

Only one youth identified a topic that should be avoided in sexuality education (1/9). This participant stated the manner in which sexuality education was discussed by other youth was not always appropriate and should be excluded from the curriculum. He clarified his opinion in the following manner:

Well I know at school you often overhear some of the kids will be talking about sex as if it were a game really, and that is not something that should be, like, they should try to make it so that kids like us should not overhear it because it sort of imprints in a way. . . . ’Cause honestly it’s probably going to lead toward things like cheating and sex before marriage. That’s in my opinion. Some people might have a different opinion on that. (Steve)

In his view, sexuality education should not be treated lightly and any discussion that did so did not have its place in a sexuality curriculum.

Caregivers reflected the general opinion that no topics should be off-limits. In Nancy's words, "I don't think there should be anything taboo." Along the same lines, Denise also felt that no topics should be prohibited: « Non, je ne pense pas (rire). . . . Les jeunes en général veulent tout savoir, puis ont beaucoup plus de questions auxquelles les adultes ne s'attendent pas je pense. » Other caregivers were more descriptive in their views about being open to all topics, as illustrated in the excerpts below:

Non, moi je pense que quand c'est bien présenté, tu sais, puisque des sujets peut-être un peu plus délicats, je le sais pas moi, les transgenres peut-être ou je sais pas si l'homosexualité c'est un sujet délicat mais je pense que c'est important de parler de tout justement et de, de donner l'information correctement, puis euh quand c'est bien présenté, quand c'est factuel puis c'est sûr que, Isabelle Hénault disait que pour nous autres la sexualité c'est beaucoup plus chargé émotionnellement que pour eux. Pour eux c'est ça, c'est justement pour ça que c'est plus difficile de leur enseigner le côté social. (Lucie)

No. I think that the more aware they are the better. I think that that's the kind of information they should have. I don't want to hide stuff from them, that's reality. . . . I think that all the facts should be at their disposal. Like I said, it's not just the, the basics that I think need to be, but the whole context needs to be addressed as well. And so, you know, what's appropriate when you see a girl you like and the kinds of behaviours to use and what's inappropriate (laughs) and that kind of thing and I think that that's not always as easily gained in a book. There's not a lot of books out there on that (laughs), I think, you know, specifically for the kids at large, I mean, because most kids they'll kind of get that social appropriateness, the lines, where the lines are drawn. (Diane)

Caregivers recognized the need for more information rather than less, but also stressed the significance of contextualizing information, as described in the previous section. Only two caregivers (2/11) mentioned that some topics should remain unaddressed. One participant discussed this in relation to sexuality education received at school. She explained,

I think with what he's (youth) gone through, with the sex education, he has learned that it's OK to talk about some things, that not to get too private with some things, with, you know, with language or something (laughs). (Katherine)

Thus, although two participants felt that some topics were meant to be kept private, the vast majority of caregivers thought there were no topics that should be barred from the context of sexuality education.

One caveat to the appropriateness of all topics in the realm of sexuality education that was raised by caregivers was the timing of topics. Indeed, just over half of adult participants felt that the timing of topics needed to be individualized according to the developmental level of the child(ren) (7/11). Participants explained that their child or children generally lagged behind in psychological and social maturity, but developed at the same rate in physical maturity. Accordingly, certain topics were seen as being broached at the wrong times for their child(ren) when compared to their neurotypically developing peers. This view is exemplified in the exchange below:

Nathalie: So you think some topics are brought up too young?

Sandra: Yes. Well I'm wondering because they're special needs if maybe they should have waited and put them, you know, and put it so that it's a later thing for them when they're old enough to understand that because a lot of it they came home and especially [younger child] didn't know that, he was telling how uncomfortable he was because he didn't understand. But they're in a regular class so they didn't really look at that. I let it go because I mean it's kind of hard, there's nothing else to do, that's what it is you know, but I wondered if special needs kids they should wait a little later to learn in high school. . . . But they're often not as mature as some other kids too, so you know, but I understand the school can't look at every kid and say "ok are you mature enough or not."

(. . .)

Marc: It's hard to do though because every kid is different.

Similarly, other caregivers expressed the timing of topics as central to the appropriateness of sexuality education as follows:

Well, it's tough because at that point you open it up and then it's all out there. So the question is when are you going to take the lid off the jar and look inside of it? Because if you want to him to have just a little peek of that little part of it, I don't think you can section it off to say "OK, you can talk about this part of sexuality but we're not going to talk about that part of sexuality." I don't know how you do that. Like I don't understand

how you can talk on a limited basis. Because I think, you know, a limited amount of knowledge is deadly. (John)

I think that it's unique to the child, right? Um, in some respects, there is a difference. And so in some ways he's younger and in other ways he's older. So it really depends on specifically what you are talking about, like the specifics of the topic, really. (Diane)

Thus, all youth felt that no topics should be taboo in sexuality education, though one participant stated that topics should be discussed seriously. Caregivers generally felt that all topics were appropriate for sexuality education, but some topics should be staggered according to the developmental maturity of each individual child.

To summarize, facts were considered important by youth and caregivers. Caregivers focused more on the safety aspect of factual information, whereas youth were more concerned with technical facts related to sexuality. Also, youth found this dimension of sexuality education to be interesting in addition to being important. Caregivers and youth generally agreed that sociosexual behavioural rules were a key component of a sexuality curriculum. Caregivers placed more emphasis on the relationship between information and sociosexual skills than did youth. Youth emphasized the need for timelines and guidelines relating to sexuality, whereas caregivers emphasized more context-specific and/or general-relationship skills. Although pleasure was a less common topic, it was closely linked to the content area of normalization of the social and sexual identities of individuals with high-functioning autism. Caregivers supported their child(ren)'s healthy sexual development. Youth and caregivers also shared a view about youths' sociosexual outcomes being normalized. Finally, caregivers and youth shared the view that no topics should be prohibited from a sexuality curriculum, but most caregivers did feel that personalized developmentally based timing of topics was an important consideration in ensuring the relevance of subject matter. Having looked at the form and the content of sexuality education, the next finding intersects these two dimensions.

**Finding 3: Overarching education.**

*All 11 caregivers defined sexuality education as extending beyond discrete classroom boundaries, requiring prompt, informal education.*

Although the first two findings dealt with the form and content of sexuality education separately, the third finding cuts across these elements and was found to be unique to caregivers. Every caregiver interviewed as part of this study (11/11) defined sexuality education as an often informal activity that extended beyond the discrete boundaries of school, home, or community. A summary of the results obtained for Finding 3 is shown in Table 6.

Table 6  
*Summary of Dimensions of the Manifestations of Sexuality Education According to Caregivers*

<b>Manifestation</b>	<b>Youth</b>	<b>Caregivers</b>
D1: Formal only (discrete)	—	<b>0/11</b>
D2: Informal only	—	<b>0/11</b>
D3: Overarching (formal and informal)	—	<b>11/11</b>

Such informal education was prompted by what I came to refer to as “critical incidents.” This finding was an unexpected discovery that I documented in my journal as requiring its own category because it did not fit with the other categories I had created:

I am starting to see a pattern when I code [caregiver] interviews. “Incidents” reported by [caregivers] that involve child and required them to act “in the moment.” One exception to this so far. Need to recode under separate category – they don’t fit in other categories I’ve created. (Journal entry, March 8, 2013)

Caregivers often provided more than one of these critical incidents during interviews as a way to help me to understand that sexuality education often happened spontaneously. These incidents involved themes that were of current applicability to youth and had not been addressed by other, more formal means. Some examples of incidents shared by caregivers can be found in the passages below:

Oh, he had a confession when I tucked him into bed. I hate confessions, they never turn out well. . . oh my God. . . . I tucked him into bed and, “Oh mom, I have a confession. Can I talk about my confession?” And I was like (hesitantly) “Yeah” and he says “But you can’t tell anyone, because I don’t think it’s OK.” He says “I don’t think it’s OK. But I have a problem” and I say “Well what’s your problem?” and he says “I touch myself down there.” And I was like “down where?.” So he gives me this look and he goes “You know.” And I go “oh. . . OH!” He goes “I do it quite a lot” and then he says to me “In fact, I’m doing it right now.” (laughs) I’m like “Well don’t! Don’t! Stop. Stop!” and I remember jumping off the bed and saying “Stop. . . please don’t do that!” and then I’m thinking “I’m probably scaring him now” because I just reacted so very badly (laughs) and we’re supposed to teach that it’s normal and it’s healthy, but ewww! (laughs). I went out and I walked down the hall and then I went back in and I sit down and I say “OK, doing that is normal” and he says “Are you sure?” and I said “I think so.” He says “You’re not a boy, how do you know?” I said “Well, I know other boys and they say it’s normal”. . . . I said “It is very normal, but not when your mother is sitting on your bed, that is weird. That is not OK.” I said “Not when other people are around, it’s kind of like a private thing. You should do it by yourself” I said “Not because you’re ashamed of it, but because it’s private. And when you do private things you should do . . .” and then we got this whole discussion of what’s private and what’s not . . . (Nancy)

But I try to make sure that they understand that it’s all natural. It’s nothing to be ashamed of, like [youth were] caught at some point with files on their computers, they had been looking at ladies with boobs and what have you, and we caught them, and, I said “You know it’s just because of your age. You’re not” – I don’t want them to feel that there’s anything wrong with it. “You’re not doing anything wrong, you’re not a bad person or anything like that, but you’re not 18 yet and as a mother I’m obligated to say that I want you to wait. When you’re 18 I’ll buy you a magazine (laughs) or whatever. You know, it’s just, you’re not quite old enough yet”. . . . I just don’t like parents who make it sound as if he did something wrong and then they go through life thinking “Oh, I’m horrible, I’m dirty” you know that kind of thing? And there’s nothing wrong with it, it’s human, you know. (Sandra)

These examples characterize how caregivers were required to provide impromptu sexuality education for their child(ren), as new situations emerged. Some caregivers mentioned how these (reactive) incidents caused them to proactively discuss sexuality with youth through recurrent conversations, as they matured. These intermittent conversations were seen as a means of ensuring that youth needs continued to be met. An example of this view is provided as follows:

But we have for years had a dialogue about sex, about sexuality and I’d say since he was little and he started getting erections or masturbating and the appropriate place where to masturbate, when to masturbate, and there is, I mean my mother’s a nurse so there was

never any hang-up or weirdness about talking about sexuality. . . . He started asking questions between 7 and 8. . . . And then he started masturbating about 10. . . . It's those rules and the social skills that they don't seem to have naturally, you know. It's like when he was younger he'd be touching himself on the couch in the living room, in front of us. It's like, [youth], when you feel that, go to your room, close the door. So that's one of the social things, where the connection wasn't made. (Ronan)

All caregivers identified that these critical incidents required some form of sexuality education. Many caregivers acknowledged feeling uncomfortable and/or ill-prepared to deal with these situations. As a result, some caregivers articulated the need for sexuality education to take place, but had not taken as active a role as others. In one instance, the caregiver had deferred to the school, as she explained below:

Katherine: It was last year . . . that he started having pubic hair, he mentioned that in a group that had girls in it.

Nathalie: At school?

Katherine: Yes! And um, now, I don't know the circumstance whether it was boys and girls in the group or whether it was just girls. But he was proud of the fact, because he was mature (chuckle).

Nathalie: What was the outcome?

Katherine: Well, I don't know other than, well I know that the teacher did speak to him about that . . . well there are certain things that you don't talk about, like *that*. . . she was a winner.

In the above instances, caregivers recognized the need for in-the-moment informal sexuality education, whether this education was provided by them or not, and to what extent.

Thus, all caregivers shared examples of incidents pertaining to sexuality education that took place outside of planned and structured situations. These incidents touched on topics that were of immediate relevance to youth and had not been addressed by any formal curricula. In this sense, this finding touched on the content (the *what*) of sexuality education. The critical incidents provided by participants illustrated how sexuality education transcended discrete areas of classroom, community, or home. As a result, this finding touched on one dimension of the

form (the *how*) of sexuality education provision. Most of these incidents were viewed as teachable moments when caregivers intervened through the delivery of improvised sexuality education to support their child(ren). Consequently, this finding touched on another dimension of the form (the *who*) of sexuality education provision. Many of these informal teaching moments were provided despite most caregivers expressing their lack of preparation; about half of caregivers (7/11) also expressed discomfort (either implicitly or explicitly) in discussing these topics with their child(ren), particularly at first. In addition, these incidents prompted some caregivers to continue to initiate periodic proactive conversations with their child(ren) to further support their healthy sexual development.

**Summary.** To summarize, three major findings were uncovered that answered Research Question 1. The major findings related to this first research question were concerned with identifying the form and content of sexuality education. The first finding looked at the form of sexuality education according to youth and caregivers. Form was conceptualized based on the dimensions of responsibility and educator attributes, as well as provision. Caregivers and youth agreed that caregivers and schools should provide sexuality education. Caregivers also acknowledged the role of community partners in the provision of sexuality education. Caregivers and youth viewed educator qualities as important dimensions of sexuality education, although the specific qualities each group identified varied to some degree. Both groups valued trustworthiness, however youth enumerated knowledge and experience about sexuality as key qualities, whereas caregivers itemized knowledge and caring about their child with autism. Regarding grouping, there was agreement across groups that a combination of 1:1 and group delivery were the appropriate modalities for sexuality education, with flexibility to meet the

needs and preferences of youth. Caregivers differed from youth in their views toward gender groupings, with caregivers supportive of more segregated options than youth.

The second main finding related to Research Question 1 was concerned with what the contents of sexuality education should and should not comprise. Facts were considered an important content area by youth and caregivers. Caregivers focused more on the safety aspect of factual information, whereas youth were more concerned with technical facts related to sexuality. Caregivers and youth perceived sociosexual behavioural rules as a key component of a sexuality curriculum. Youth emphasized the need for timelines and guidelines relating to sexuality, whereas caregivers emphasized more context-specific or general relationship skills, with a link between information and behaviour. Although pleasure was less common a topic, normalization of the social and sexual identities of individuals with high-functioning autism was more present and nonetheless linked to enjoyment. Caregivers supported their child(ren)'s healthy sexual development; both groups also held normalized views toward youths' sociosexual outcomes in adulthood. No topics were deemed outside the scope of a sexuality curriculum. Most caregivers supported modifying the timing of curriculum to meet youths' developmental needs.

Finally, all caregivers shared examples of incidents pertaining to sexuality that took place outside of a formalized sexuality education setting. These critical incidents required immediate, informal education. Consequently, sexuality education was conceptualized by caregivers as transcending classroom boundaries and formalized curricula. Having reviewed the conceptualizations of sexuality education put forth by youth and their caregivers across the dimensions of form and content to answer Research Question 1, I now turn to Research Question 2.

**Research Question 2: *How do prior literature, policy, and curricula in this field inform this definition?***

**Finding 4: Extant textual evidence.**

***Generally, sexuality education definitions provided by youth and caregivers were well-supported across the literature and curricula. No policies were found that pertained specifically to high-functioning autism and sexuality education, however, broader policies on sexuality education did support the definitions, albeit to a lesser extent.***

Finding 4, which answered Research Question 2, is discussed in Chapter 6. The subsequent chapter uses extant texts to provide an in-depth review of the fourth finding, which informs the first three findings derived from Research Question 1. To assist in the visualization of the results and supporting evidence for Finding 4, appendix Tables U1, V1, and W1 are provided to illustrate the various dimensions of sexuality education enumerated in Findings 1, 2, and 3, defined by youth and caregivers, and informed by recent relevant literature, policy, and curricula/resources (see Appendices U to W).

The first research question looked at creating a definition of sexuality education, as conceptualized by youth with high-functioning autism and their caregivers. Having painted some broad strokes of the ways sexuality education can be conceptualized according to these informants, I now examine the supports and barriers that facilitate or hinder access to sexuality education for these youth.

**Research Question 3: *In the context of sexuality education for youth with high-functioning autism, what are the supports and barriers encountered by these youth and what are their impact(s)?***

Having arrived at a conceptualization of sexuality education informed by youth with high-functioning autism and their caregivers, I was concerned with what supports and barriers youth may encounter in accessing sexuality education. Findings 5 through 8 were related to these supports and barriers. Although Findings 5 and 6 focused on personal strengths and external supports, Findings 7 and 8 revolved around personal and societal barriers.

### **Finding 5: Individual strengths.**

*Regarding individual strengths, youth and caregivers differed in that many youth struggled to identify personal attributes related to sexuality education, whereas all caregivers were able to identify a number of strengths for their child(ren), including intelligence and affective empathy. Openness was identified as an attribute by most caregivers, but only one youth.*

Finding 5 concentrated on the individual strengths identified by youth and their caregivers. A summary of the results obtained for this finding is shown in Table 7.

Table 7  
*Summary of Individual Strengths Identified by Youth and Caregivers*

Individual strengths	Youth	Caregivers
IS: Overall	Struggled to identify specific attribute (9/9)	Able to identify with ease (11/11)
IS1: Openness	Explicitly stated (1/9) Demonstrated (8/9)	9/11 <sup>a</sup>
IS2: Intelligence	1/9	11/11
IS3: Empathy	0/9	6/11
IS4: Concrete thinking	0/9	5/11 <sup>a</sup>

<sup>a</sup>Also explicitly identified as a potential barrier by some.

**General attributes.** Caregivers were able to list a number of individual attributes for their child(ren), whereas youth struggled somewhat with this question. Youth had a difficult time providing personal strengths or attributes related to sexuality education, but were generally able to provide more concrete attributes. Indeed, all nine youth (9/9) were able to describe concrete personal attributes. Many participants identified ease with technology and skill at gaming as personal attributes. One participant who had indicated video games was a strength responded to the question as to whether he was good at them with “Very” (David). Along these same lines, another youth stated: “Hacking. Hacking into the computer to get unlimited access to the Internet. I was thinking of getting my own modem so I can just connect to it at night and go on

the Internet” (Rick). Youth provided clear descriptions of their concrete personal strengths, and did so with honesty and depth:

Me, I’m a person that likes to get work done. Like if I get an assignment, I do it as quick as I can, I don’t rush through it, I make sure I look over it while I’m doing it, I like to get work done early so I can do other things to learn. . . . Yeah, that’s one benefit. Another benefit is trying to help others, because if I need help, I ask someone I know well, I’m not a person who’s afraid to ask somebody, to an extent, if I know the person doesn’t like it I won’t ask them. Otherwise I’ll ask people for help. (Jeremiah)

I’m always being told that I’m very smart . . . I get told all the time that I always try to do my best at work and such. And I try to basically be the best I can be and I’ve been told that I’m a nice person, I try to help others. . . . Well one thing I know now is once I get used to a routine, like the way I have to walk to get from work, I can do it over and over without too many problems. The problems come when I have to change that routine, but I’m finding that as I get older I can find ways to work around changes. And that’s no doubt been helped through the work that my resource teachers and my parents put in. (Steve)

In this sense, most youth were able to provide a variety of concrete personal strengths. However, youth were not able to link these concrete attributes in a way they found useful in the context of sexuality education. On this point, some youth provided an example of a concrete attribute followed by a statement explaining that the attribute was not relevant for sexuality education. An example of this is put forward below:

Non, c’est juste en maths que je suis extrêmement, extrêmement doué. Comme je retiens l’information. Comme j’avais juste des A. . . . Mais je ne sais pas ce que ça pourrait amener à un cours de sexualité. Je suis très bon en histoire, j’adore l’histoire, qui encore une fois m’amène majoritairement aucun avantage à la sexualité. (Zachary)

Therefore, although youth struggled to identify relevant attributes with regards to accessing sexuality education, they were able to provide more general personal attributes.

**Openness and intelligence.** Only one youth identified openness toward the subject of sexuality as a personal strength (1/9). On this topic, Daniel explained simply that: « Tout ce que je peux dire de moi c’est que rien ne me dérange pour autant. . . . C’est que je suis un garçon très patient. . . . Ah oui, et je suis quand même intéressé à ça (l’éducation à la sexualité) là ». Though

only one youth identified openness or ease with the subject as a personal strength, an overwhelming majority of youth (8/9) actually held this attribute, as displayed during the interview or as reported by their caregivers. This openness and comfort was often communicated as an *absence of discomfort* by youth. This attitude was reflected in Justin's responses:

Justin : Juste euh qu'est-ce que. . . Ben, juste qu'est-ce qui, y'avait des réponses. Et y jasant aussi. Ils [les gars de la classe] pensent c'est un petit peu dégueulasse, parce que, de qu'est-ce qu'on parle, nous les gars.

Nathalie : Toi, est-ce que tu pensais ça aussi?

Justin : (hoche la tête pour dire non) Moi, j'ai déjà écouté ça, dans ma classe l'année passée.

Nathalie : Alors toi ça ne te dérangeait pas?

Justin : Non.

Similarly, in speaking with Jason, there was again no sense of discomfort regarding the topic or the person with whom this topic was discussed:

Nathalie: So it would not make you uncomfortable if it was your teacher teaching you?

Jason: No, no difference.

Nathalie: And it wouldn't make you uncomfortable if it was your mother teaching you about it?

Jason: Probably not.

Moreover, an overwhelming majority of youth displayed the particularly relevant personal attribute of openness and comfort with sexuality education, but did not recognize this strength in themselves. Thus, youth held many personal attributes that were relevant to sexuality education, but were either not able to identify the strengths, or were unable to connect them to sexuality education.

Unlike youth, all caregivers were able to enumerate a number of personal attributes for their child or children (11/11). Intelligence, specifically, was identified by every caregiver

interviewed (11/11) as a personal attribute for youth, but by only one youth (1/9). One caregiver discussed intelligence in the context of education, stating:

Well I hope he does some post-secondary education of some kind. I think that would be to his benefit. He's very smart, I think it's more of an issue of focus. We have lots of work to do on that. Yeah. Uh, he, like I said, he's very intelligent, that's not an issue.  
(Diane)

Another caregiver also made the link between intelligence and education when she said "Well, I, academically he's got it . . . He's OK academically" (Katherine). Speaking more generally, Ronan described his child's intelligence in the following manner: "I mean, [youth] is great, I mean he's really intelligent, so he'll find what he has to find." In this instance, intelligence was synonymous with resourcefulness, a useful attribute for youth seeking to learn about sexuality.

Along with intelligence, the attribute of openness or comfort with the subject was identified as a personal strength by the majority of caregivers (9/11). This was described by a few caregivers as being a wholly positive quality. For example, one participant stated « Je trouve ça l'fun y'est ouvert, fait que s'il se pose une question, il va venir me voir moi ou voir son père » (Lucie). Another participant expanded on the positive aspects of this attribute thusly:

La façon que [jeune] parle, il n'est peut-être pas représentatif de tous les Aspergers, mais tu sais, pour lui, il a besoin de savoir comme qu'est-ce qui est bien, qu'est-ce qui n'est pas bien, tu sais, ça l'inquiète beaucoup. Parce que aussi ça lui donne un peu de sentiment de sécurité même si les autres n'agissent pas comme ça, au moins lui il sait que c'est la bonne chose à faire et c'est la même chose pour comme l'homophobie ou le sexisme des choses comme ça, comme pour lui . . . y'est capable d'être ouvert à des choses beaucoup plus matures que son âge, comme dans des livres, ou des romans, ou des films, et d'en discuter comme vraiment simplement et ouvertement et de faire un peu de différence, de pas être trop influencé, tu sais. Par ce qu'il voit, ce qui est représenté et tout de suite comprendre que « OK, ça ce n'est pas la réalité. » Oui. (Denise)

Interestingly, this and other attributes were seen as both strengths and challenges. In this sense, qualities were sometimes conceptualized as having positive and negative effects. This became apparent to me when I was coding transcribed interviews according to the themes of "support" and "barrier," described in the following journal entry:

When coding, I am starting to see a pattern of green/red close together, even overlapping [green: support; red: barrier]. Sometimes having a hard time deciding which one it is – often choosing both. Need to create category for these double-coded segments. Catch 22? Double-edged sword? (Journal entry, March 12, 2013)

Most of these caregivers (7/9) were ambivalent toward this attribute, recognizing that openness could act as both a strength and a barrier, depending on how others interpreted it. For example, one caregiver identified her own appreciation and difficulty in dealing with her child's direct demeanour, as seen in the following statement:

If he wants to know, then he asks it. And I'm very lucky because [youth] is very honest with me. OK, I feel lucky or unlucky, it depends on the day. When I'm really stressed out and he asks me a weird and wonderful question it freaks me out a little bit, but I don't have to guess. Like with [youth], I never have to guess. I know exactly where he's at and if I ask him, he'll answer. Like if I decide we're going to have a sex talk with him today, well . . . he'll have that conversation with me. And he'll sit right down and yeah, whatever you want to know, he'll tell you. (Nancy)

Similarly, the ways in which openness worked as a positive and a negative attribute were reflected in a discussion with Alina and Ronan:

Ronan: Well he was trying to lie, but it didn't go so well. But [youth's] default is honesty. He does something, whether bad or good, he comes back and talks about it. Which is great in a sense because all of the stuff isn't being hidden, and you're not – and you get a chance to rapport with the child, all of that stuff is being discussed after, so. Whatever happens. So it's good. I think it's a real strength, [youth], it sometimes has challenges when we don't filter the right thoughts, but as a rule, that is a real strength that we can talk about these things. . . . Like the first time he masturbated he went to school and told the teacher and the whole class. Which is interesting because other kids would be mortified.

(. . .)

Alina: And I remember I was taking [daughter], our oldest one, she is 22 now, she was in the car. The first thing, he didn't even get in the car, he just opened the door and says "I did it! I masturbated!" and the oldest one was "*Oh my God!*" she was so uncomfortable!

(. . .)

Ronan: But again, the fact of the honesty is that, regardless of bad or good, we have a chance to talk about it afterwards. And that is huge. Because there's nothing worse as a parent, kid going down a road, and I've seen this with some of my friends, kid going down the road, down the road, down the road, something awful happens and it's like

there's been this whole time where this kid has been deviating off and the parents are completely disconnected.

The attribute of openness was therefore seen as both a strength and a challenge by caregivers, depending on the context. In general, caregivers identified it as a strength that was perceived as a barrier when misinterpreted by others who lacked understanding of the autism profile. Similar to openness, concrete thinking was identified as a strength by some caregivers (5/11), but also as a potential barrier (10/11). Concrete or "black and white" thinking was most often associated with youths' personal convictions and/or factual information. One caregiver expressed strong personal convictions as a distinct strength:

[Health care professionals] told him to never drink any beer. He already blocked that, and I'm sure he'll never smoke, or do drugs, I mean he's very definite about it. Because his mother and sister are chimneys as far as smoking goes. And it's just bad. Yeah. But anyway, he's well aware of all those, all of those things. He's a good kid. He's a good kid. He's got good morals. (Katherine)

Another caregiver, while also expressing well-defined personal convictions as a strength for her child, also went on to express the need for her child to learn about the nuances involved in the realm of values:

Comme je pense que, des jeunes à l'université ils font des semaines sur l'éducation sexuelle et ils parlent, par exemple, de consentement et de relations amoureuses . . . ou la prévention du viol. . . Vu que pour lui c'est important aussi que tout le monde comprenne ce qui est correct et ce qui n'est pas correct, je pense que ce serait bon pour lui de trouver un peu comme un juste milieu entre ces deux choses-là. Je pense qu'il y aurait des personnes qui pourraient vraiment apprécier ces choses-là chez lui. . . Y'a ce côté-là qui est bien, comme d'une certaine manière c'est quelque chose qui est comme positif chez l'Asperger. Par exemple, parler de la cigarette ou des drogues, comme pour lui ça fait longtemps que, quand y'a commencé à être dans ces situations-là, pour lui c'était clair, puis il n'a pas eu de pression des pairs . . . pour lui c'était complètement décidé. Mais en même temps je pense que c'est important qu'il voit autre chose. Qu'il voit que, les relations humaines c'est pas toujours si simple et si direct. Et il faut accepter que les autres n'ont pas toujours la même opinion que nous, ils n'ont pas fait le même cheminement aussi directement que nous.

Hence, although some caregivers identified concrete thinking as a potential positive attribute, many more identified this attribute as a barrier. This result is further discussed as part of Finding 7.

**Empathy.** One surprising discovery was caregivers' identification of empathy as a strength for their child(ren). As one caregiver put it

Il peut avoir un certain niveau d'empathie. C'est assez étonnant parce que des fois, il me lit mieux moi, il va savoir plus mon état émotionnel que mon mari, mettons. Oui. Il est étonnant sur des détails, peut-être. . . . Fait que y'a un certain niveau de perception, d'observation, d'empathie. (Lucie)

Indeed, more than half of caregivers (6/11) stated their child(ren) were (eventually) able to recognize when others experienced emotional distress and displayed a response, and that this empathy was a definite strength. Generally, the empathy described by caregivers was of a more affective than cognitive nature. In this sense, youth may have initial challenges in recognizing an emotional state in others, but once deciphered, were able to respond to such an emotional state. In addition, caregivers explained that youth may not always feel the same emotion as another person, but did feel distress in response to another person's emotional state. More to the point, youth often sought ways to remediate a situation for another person. Below is one example of this unique embodiment of empathy:

I remember that one time I cried . . . and I cried and it felt like my heart was broken and everything sucked. . . . So my son is looking at me kind of like under a microscope and he says "Well maybe you should lay down if you don't feel good" . . . and so I go upstairs and I lay down. And then he, cause he loves me very very much, so he sort of comes around the door and he says "You know mom, maybe you need me" and I said "Maybe I do. Maybe you should come lay down with me" and he said "I can do that, can I cuddle you?" and I said "Yes" and he comes in and he cuddles into me and he's so upset at this point, not upset in an emotional way, but distressed, like jittery and he's shaking and he doesn't like it. So I feel really badly and I tell him "I'm really sorry [youth], you know that I'm so upset" and [the youth] says "Don't feel sorry for me mom, feel sorry for yourself!" and I remember . . . I stopped crying entirely and I looked at him . . . and so he looks at me and he says "Was that the right thing to say? I got it on TV. If it doesn't work I'll find something else." (Nancy)

A similar example of empathy was described by France and John:

John: He's very very kind. Yeah.

France: And generous.

John: . . . Well, he *is* selfish, he can't help that, it's just what he is. But when he does it and he sees what he's done, it really upsets him and tries not to do it again, right? And uh, you know, cause he needs to do what he wants to do right now, and then when he realizes that his insistence has hindered everybody else from trying to do what they were doing, he's all "Oh I won't do that, I didn't know, I didn't know" because he gets so focused, but he's kind on the other side, which is, he wouldn't do anything mean spirited which is good.

(. . .)

France: Or he wants something really really bad, like he wanted to go out with her (schoolmate). But then he will be generous, like he would be good, like us at home he always offers to share. Or he paid for a friend one time to bring him to the movies because he wanted to go with somebody, so he's generous from that perspective.

Thus, many caregivers identified ways their child(ren) demonstrated empathy toward others, including some unconventional ways. This personal strength was not identified by youth. It was a surprising finding because it went against traditional conceptualizations of autism.

**Summary.** In summary, caregivers were better able to describe personal strengths related to sexuality education for youth with high-functioning autism. Youth were able to list more concrete and general personal attributes. In general, many of these attributes could have been linked to sexuality education; however, youth were not able to make these connections. Caregivers, for their part, listed intelligence, empathy, openness, and to a lesser extent, concrete thinking as primary personal strengths. However, some of these attributes were also potentially perceived as barriers in certain societal contexts. From a socially inclusive perspective, this finding gives pause in reassessing how personal strengths and barriers are understood. It would appear that certain attributes can function as strengths or as barriers, depending on the context. Thus, the current incarnation of the socially inclusive theoretical framework proposed for this

study may provide an incomplete understanding of personal strengths and barriers; further refinement may be required. The following finding explores the external supports identified by youth and their caregivers.

**Finding 6: External supports.**

*Youth and caregivers both identified caregivers and other trusted adults as supports in accessing sexuality education. Youth and caregivers differed regarding Internet/media; youth identified Internet/media as potential resources, whereas caregivers perceived them as potential barriers.*

Whereas Finding 5 centred on individual strengths, Finding 6 looked at external or societal supports for youth in accessing sexuality education. A summary of the results obtained for this finding are shown in Table 8.

Table 8  
*Summary of External Supports Identified by Youth and Caregivers*

External supports	Youth	Caregivers
SS1: Trusted adults	7/9	11/11
SS2: Internet	7/9	0/11 <sup>a</sup>
SS3: Peers	3/9	5/11

<sup>a</sup>Explicitly identified as barrier by some.

**Trusted adults.** Youth and caregivers concurred that caregivers and other trusted adults acted as the primary supports in accessing sexuality education. Indeed, seven young participants shared this view (7/9). Youth generally identified caregivers, extended family, and/or teachers as supports. One youth put it succinctly when he said: “Well the biggest one [support] right now is by far my parents and the people who I know I can go to, like resource [room] or teachers” (Steve). Another participant explained why various people were deemed good supports in the following excerpt:

Ma mère (rire) a une très grande connaissance, donc j’ai déjà une bonne connaissance. . . . Mes tantes, parce que la majorité de . . . ma famille du côté de ma mère étaient enseignants, ils sont très très, pas sages, mais connaisseurs. Sur la majorité de

tout. C'est une tradition d'être professeur. . . Mais comme ma tante. Puis si je m'en vais du côté religieux, j'ai mon oncle, très vieux, il est un prêtre. Si je veux aller du côté plutôt sérieux, médical, je m'en vais vers ma mère. Si je m'en vais vers contraceptifs et drogues – ma mère. Si je m'en vais dans les risques, ça serait ma tante, très créative, très drôle. Euh, des choses comme ça. (Zachary)

Caregivers fully agreed with youth that caregivers themselves and other trusted adults were primary supports in accessing sexuality education (11/11). Although more than half of caregivers (7/11) mentioned that they experienced discomfort when providing sexuality education to their child(ren), most stated that they would offer such education nonetheless. As an example, when asked if he would feel uncomfortable if his children asked him about sexuality, one caregiver responded in this manner: “At first yeah, but if it has to be done, it has to be done” (Marc). In this instance, the caregiver acknowledged the need to provide sexuality education despite discomfort. As such, although discomfort was present, it was not seen as an obstacle to meeting the educational needs of youth. This finding was well supported by the survey results. On a scale of 1 to 5, a mean of 4.15 was obtained for the communication subscale. This score indicates that caregivers reported being adept at communicating about sexuality with their child(ren) and other stakeholders. This is in line with the finding that caregivers discussed sexuality with their children (as reported in Finding 3). In addition, survey results also indicated that on an item specifically measuring this aspect of the construct, most caregivers (5/8) were generally comfortable talking about sexuality with youth. Finally, survey respondents viewed themselves as somewhat competent educators, with the competence subscale obtaining a mean of 3.64 on a scale of 1 to 5.

Caregivers expressed their unconditional availability to their child(ren) to discuss sexuality education. During an interview, one caregiver discussed the importance of being available:

Well they know that we are always going to be here for them no matter what. It doesn't matter what happens to us, no matter what, we're always there. And they've been told that three million times, not to worry. (Sandra)

This point of view was echoed by another participant thusly: "He knows that he can always talk to us. And we will be willing to talk, if we don't know the information, I'll find out" (Alina).

Survey findings supported the view that caregivers shared the attribute of knowledge in educating youth about sexuality. On the construct of knowledge, a mean of 4.19 was obtained along a scale of 1 to 5, thereby indicating that caregivers perceived themselves as knowledgeable about sexuality.

In addition to unconditional availability and knowledge, one participant elaborated on the importance of ensuring that caregivers indeed act as good supports for their children. She explained that it was important to adopt healthy attitudes toward sexuality and to transmit those to her child. She expressed her view in the following manner:

So everything that I've learned or I'm a product of, I pass on, whether on purpose or by accident to my children. So we have the potential to teach them great things, like how to be young once and how to feel joy and how to not be sexually inappropriate or just plain inappropriate when we go in public, on the same hand we have the same opportunity to pass on any hang-ups or any issues that we have from our own childhood whether we're willing to face them or not onto those minds. . . . And he's looking for connections because he doesn't have the emotional connections, so he's trying to put a logical connection in, so the information I give him is very important. . . . I don't want my hang-ups to be his hang-ups. And my hang-ups, whatever they are . . . they're not healthy. Sexuality is healthy, whether we want to talk about it or not. It's a part of who we are . . . So if you have a natural and healthy attitude towards that, then you have a more natural and more healthy attitude towards relationships. And when you deal with children with Asperger's, they're already behind when it comes to relationships, so by giving them a solid base in sexuality, it's also giving them an opportunity to have more meaningful, healthy relationships. Because sexuality is part of interpersonal relationships. (Nancy)

Other caregivers mentioned the importance of other trusted adults, especially in the context of school or the transition into adulthood. On this topic Lucie stated « T'as besoin, je pense, d'un fil conducteur, un peu comme un parent à l'école. Tu sais un point de référence à

l'école. » Relatedly, another caregiver described the role of key persons in school and beyond in promoting the sociosexual development of youth:

He's been really . . . the main guy in the board. For autism, especially. He's a super fantastic guy. He's not in that area anymore, but he was there when we needed him, and he was super. He was excellent. So we've had a lot of good supports. And the developmental services ladies are super. [Developmental service worker] has been super. . . . So we've had a lot of good support. Uh-huh. (Katherine)

This caregiver expressed the importance of various stakeholders – conceptualized as people who care about the child and family – coming together to provide wrap-around services for youths as they develop. Therefore, youth and caregivers shared the view that caregivers and other trusted adults are the primary external supports in accessing sexuality education. Various individuals were named in addition to caregivers, including: teachers, other educational professionals, extended family members, and developmental support workers.

**Internet.** In addition to trusted adults, most youth also identified the Internet as a resource (7/9). This was a surprising finding that at first had been coded as part of other supports, but was then later recoded independently of others, as it was such an omnipresent element of my conversations with youth and with caregivers. As this theme became more and more apparent, I made note of it in my journal:

As I read and reread all of the transcripts, I am wondering if media/Internet/porn should probably be its own category because it figures so prominently in practically all of the interviews in one way or another. More positively with youth; more negatively with caregivers. (April 8, 2013)

Although most youth cited the Internet as a support, they did so with reservations. As some participants explained, the Internet could be a good source of information, but was also rife with misinformation and should therefore be approached with caution. Steve, for example, explained his point of view as follows:

Steve: Like chances are, if I really needed the info and I couldn't go to them (caregivers) I could use the Internet for that sort of thing, but it's never happened yet and at the same

time I've learned that you have to be sort of careful about the Internet because pretty much anybody can change it as they go.

(. . .)

Caregiver: It's not all true, what you read.

Steve: Yes, pretty much.

Caregiver: It's good that you know that.

Steve: I also know that you should never use Wikipedia as a reference for school projects. . . . Because everyone can get on it and change it around.

Caregiver: Oh, I didn't know that.

Along these same lines, Zachary described the limitations of the Internet for reliable information:

Zachary : Si j'étais désespéré, pis y'avait pas Wikipédia, je suis jamais allé à Wikipédia parce que je trouve que c'est – c'est quoi encore le contraire de fiable? – ça ne se dit pas « infiable. » Non. Parce que tout le monde, c'est public, tout le monde avec un. . . . Un compte, peut modifier n'importe quoi sur Wikipedia donc je trouve que c'est pas très fiable.

Similarly, some participants described their view of the Internet as a potential source of information and misinformation. In addition, the Internet could also be a source of too much information for them, as explained in the following exchange:

Nathalie : D'autres ressources? Comme les livres, l'Internet?

Daniel : Euh, ça dépendrait. Comme, y'a certains sites qui existent sur l'Internet qui sont correct là, mais les vidéos qu'on trouve n'importe comment ce serait un petit peu étrange là.

This was also expressed by Jason in his conversation with me on the topic of external supports:

Nathalie: When it comes to resources, what would you consider a resource for sex education?

Jason: Internet and logic. Internet and brains. . . . I remember this site on the Internet, it was actually one of the smarter people. The whole thing that people don't give a kid enough credit, and yeah, I'm gonna, and assuming that we're not completely impressionable. . . . Basically, the Internet can provide all the information you need, as long as you're smart enough to get through and sort through it all.

(. . .)

Nathalie: Have you ever used the Internet to look up information about sexuality education?

Jason: Purposely? No. But it's kind of hard not to stumble across them though. Oh man – yeah.

Nathalie: What have you stumbled across?

Jason: Infor . . . Quite a bit of information and I – can I skip this question?

Nathalie: Yes. Did you find that information useful?

Jason: Yeah, I suppose I did. In fact, I learned more about it than I probably, than I probably, than I probably learned in school . . . I've learned enough that I'm not gonna be taken by surprise.

Others had previously used the Internet as a proxy for accessing caregivers. This was the case for Jeremiah who stated

Sometimes I would use the Internet, whenever I was younger and I was more afraid and I did not know what was going on. Because I didn't know I had the problem (autism), I would use the Internet. Now, I go more to people. I do not turn to Internet as much.

Other participants had used the Internet specifically for social or sexual ends. For example, some youth had used the Internet to access pornography. This was also reflected in survey results, with a third of youth (2/6) reporting they had accessed online pornography. One youth had used the Internet to try to find a girlfriend, which resulted in getting into trouble with his parents. He explained his experience and the consequences thusly:

Justin : Oui, je sais des sites web. Y'en a un qui s'appelle Zoosk mais j'ai pas le droit. Ça c'est pourquoi que j'ai eu un affaire de « parental control, » ça m'énerve parce que ça dit ça à chaque fois que je veux aller comme à Zoosk ça dit y'a un parental control, puis tu peux cliquer les check marks pour les enlever mais ça juste continue et continue et ça m'énerve. Après j'ai joué un jeu avant que, mais la semaine après maintenant il me laisse pas entrer. Après il savait que c'est un jeu « parental control, » so c'est pourquoi ça me laissait pas. J'ai joué, ça marchait avant puis maintenant ça marche pas. Ça marche n'importe où excepté ici. Si j'ai pas le « parental control. »

Nathalie : Pourquoi est-ce que tu es allé à Zoosk?

Justin : Ah parce que je disais je voulais avoir une blonde mais ça marche pas, c'est pour les adultes. . . . Oui, je savais déjà ça, mais je pensais que c'était pour les adolescents aussi, comme 13 ans ou quelque chose.

Thus, most youth perceived the Internet as an external support for sexuality education, but many also viewed the Internet as an unreliable or even dangerous place. Youth approached the Internet and the information obtained from it with caution. This finding was in stark contrast to caregivers who generally perceived the Internet as a potential barrier to sexuality education.

**Peers.** A small percentage of youth identified peers as potential supports (3/9), whereas lack of peers was cited as a barrier, as will be further explored in Finding 8. When discussing external supports, one youth exclaimed the following: “I’ve got lots of friends!” (Rick). Another youth described how his peers had supported him from a practical sociosexual perspective when he tried to get a girl to go out with him:

Justin : Ben j’essaye d’en faire [trouver une blonde], en demander une pour sortir avec moi mais y dit non, y veut, s’intéresse pas.

Nathalie : Est-ce que t’aimerais ça avoir de l’aide avec ça (trouver une blonde)?

Justin : J’ai eu déjà de l’aide avec des gars de ma classe, y m’ont aidé, puis après . . . [elle] dit oui à moi.

Nathalie : Comment est-ce que les gars t’ont aidé?

Justin : Mais juste, en premier, en octobre, quelqu’un a aidé mais ça pas marché. Parce que j’ai demandé à une fille puis je voulais sortir avec, mais elle a dit non. Mais après j’ai dit je veux vraiment sortir avec elle mais elle veut pas encore. Mais ça pas allé.

Nathalie : Qu’est-ce qui est arrivé?

Justin : On a juste décidé de pas faire la date [sortie].

Nathalie : Tes amis t’ont aidé comment?

Justin : Ben ils ont juste dit, ben ils ont juste parlé à la fille après « Ben, [Justin] veut sortir avec toi, tu dois lui dire oui. » Après la fille a dit « Je sais pas, y’est pas vraiment mon type. » Mais après ils ont dit « Ben tu devrais sortir avec lui, donne-lui une chance. » Puis après elle a dit « OK, d’accord je vais juste le faire pour lui. »

As demonstrated above, a few youth did see peers as potential supports in developing their sociosexual skills at a more informal and practical level. However, as will be discussed in detail at a later point, the help provided may actually work against the individual. In the example

above, Justin's peers exerted peer pressure on a girl to agree to go on a date with him. This kind of peer pressure, although perhaps well-intentioned, may send an inappropriate message to Justin in terms of how he should behave. Further, this pressure did not result in a positive outcome for Justin (i.e., no date ensued). Finally, it appears that Justin did not understand that his friends were not acting in a helpful or appropriate manner.

As was the case for some youth, some caregivers identified peers as potential supports (5/11), and, in line with youth again, caregivers identified lack of peers as a barrier.

Unsurprisingly, caregivers with children who had friends were more likely to identify them as supports. Peers were identified as a support by one caregiver in this way:

But his literalness will go against [him] . . . unless he gets the right person, like his best friend – luckily he's had a good best friend that understands him, you know, and knows that when he gets loud and when he doesn't quite understand. And maybe when he said something as a joke that he doesn't know that he's not being funny he just lets it go because it's [youth]. (Sandra)

Although more caregivers identified peers as supports, they were also more cautious about the extent to which peers could provide useful and accurate information on the topic of sexuality education. Some participants again mentioned the developmental lag that existed in their child's peer group as a potential limitation to these peers acting as an effective support when it came to sexuality education. Nonetheless, peers were seen as holding an important supportive role by both caregivers and youth.

**Summary.** To summarize, youth and caregivers both agreed that caregivers and other trusted adults were central supports in accessing sexuality education. Youth and caregivers also agreed that peers could be a good support, but that most youth did not have an adequate peer group for this to be the case. As a result, lack of peers was cited as a barrier, as will be further discussed in the following findings. Youth and caregivers differed about the supportive impact of the Internet. Youth viewed the Internet as a potential resource, though one that should be used

with caution, whereas caregivers generally perceived the Internet as a potential barrier to accessing appropriate sexuality education. Understood through a socially inclusive lens, trusted adults act as formal and informal supports in their role of educator. Such an assessment is aligned with the definition of educator proposed in the first finding. Peers, for their part, also fit well into the theoretical framework as supports or barriers, depending on the roles they adopt. As with peers, the Internet (and other media/technology) can be mapped onto the theoretical framework as both a support and a barrier, depending on the vantage point (youth or caregiver) and the ways in which they are used. Further discussion on this point is forthcoming. Whereas Findings 5 and 6 were concerned with personal strengths and social/societal supports, the final two findings focus on internal and external barriers to sexuality education. These findings are addressed next.

**Finding 7: Personal barriers.**

*Overall, caregivers were better able to identify personal barriers for youth than were youth themselves. Primary barriers identified by caregivers and youth were literal thinking, maturity, sensory issues/anxiety. A barrier identified by youth but not caregivers was that of poor self-image/confidence.*

Findings 5 and 6 examined the internal and external supports for sexuality education for youth with high-functioning autism. In contrast, Findings 7 and 8 revolved around the personal and social/societal barriers limiting access to sexuality education for these youth. A summary of the results obtained for Finding 7 are shown in Table 9.

Table 9  
*Summary of Individual Barriers Identified by Youth and Caregivers*

Individual barriers	Youth	Caregivers
IB – Overall	None identified (3/9)	—
IB1: Low self-perception	3/9	0/11
IB2: Sensory/attention/anxiety issues	3/9	9/11 <sup>a</sup>
IB3: Concrete thinking	1/9	10/11 <sup>b</sup>
IB4: Delayed developmental maturity	0/9	10/11
IB5: Openness	0/9	7/11 <sup>b</sup>

<sup>a</sup>Also implicitly identified as strength by some; <sup>b</sup>Also explicitly identified as strength by some.

**Low self-image and sensory issues.** For personal barriers, youth were again less able to self-identify or articulate their own needs. No overarching barriers were found across all youth. In fact, a third of youth interviewed stated that no barriers prevented them from accessing sexuality education (3/9). As one youth put it “There’s no obstacles” (David). When asked about personal barriers, another youth explained that none existed because he had a higher functioning form of autism. He stated, « Non, pas moi. Je suis autiste de très haut niveau avec le syndrome d’Asperger » (Zachary). Other youth did identify barriers, though none were ubiquitous. A noteworthy barrier reported by some youth but not by caregivers was that of poor self-image or self-confidence (3/9). This was evidenced in the following exchange with Chris:

Nathalie: So say you didn’t have a choice, you had to have sex ed -

Chris: What would they talk about?

Nathalie: They would talk about relationships and -

Chris: I think I would want that. I think so.

Nathalie: And they would talk to you about how to meet someone, how to ask someone out on a date, how to keep a relationship going.

Chris: Oh (dejectedly). I think that the majority of the people in my school are not as broad as me.

Nathalie: Broad in what way?

Chris: (makes the sign of a big person with his arms). That.

Nathalie: OK.

Chris: I'm not really fat, but my mom says "chunky." Like a chunky soup!

Nathalie: You think you're "chunky." What do you think that has to do with sex ed?

Chris: I have no idea! I think it just means that, since my appearal [appearance] is different than most of the kids at my school, I think people would not really want to chum up or go out on a date with me.

Along the same lines, Jeremiah expressed how his negative self-image impacted his ability to benefit from sociosexuality education.

Jeremiah: Um, I'm not very good at picking my strengths, because I judge myself a lot. That's one of my big problems, I judge myself too much.

Caregiver: Too hard.

Jeremiah: No, too much. Especially on how I look because I find my physical appearance, it bothers me quite a bit. Sometimes it makes me feel like there's nobody who wants me – like in a relationship. It's kind of sad because I have friends who have the same problems, yet I kind of feel hopeless and helpless because they have had relationships and I have never had one and there's still people who like them and would go out with them, so. That's why my disadvantages slow it down even more – to understanding it.

This was a surprising finding because it required a level of self-awareness that has not historically been associated with autism spectrum disorders. Moreover, it was a barrier that was uniquely brought forth by youth, not one that had been identified by their caregivers. Thus, for those three youth who did identify this barrier, it seemed to be of particular importance and relevance to them and the topic.

Some youth identified anxiety or sensory issues as a personal barrier to accessing sexuality education (3/9). One youth described his difficulty in staying focused and listening for extended periods of time as a potential challenge in learning about sexuality. This point was raised when he was asked about who he believed would be a better sexuality educator:

Nathalie: So what about your dad? Would your dad be able to answer your questions about sex?

Jason: Definitely. The question is, the question is whether I would manage to stay focused.

Nathalie: Would *you* manage, or would *he* manage?

Jason: He would manage, probably. . . the question is whether *I* would manage to listen, to actually keep listening.

Although Jason was the only youth to identify this challenge, many participants actually exhibited this challenge when being interviewed, reinforcing the earlier statement that youth were less able to self-identify personal barriers.

Caregivers, for their part, were generally more articulate about their child(ren)'s personal barriers. Most of the barriers elicited by youth were echoed and emphasized by caregivers. For example, sensory and related issues were elicited as barriers by the vast majority of caregivers (9/11). This concern related both to accessing sexuality education, and to negatively impacting personal expression and experiences of sexuality. For example, one caregiver described the impact of a tactile sensory issue for her child:

What did he talk about the other day? Hair? It was about hair near his penis or down there, and I was trying to tell him it was a good thing because it meant he was becoming a big man now and he told me it was disgusting and how could he get rid of it and now his skin is not soft anymore and this is not OK because it is the tactile part, he doesn't like the feel of it. (Nancy)

Analogously, another caregiver described various sensory sensitivities and their impact on the family:

Sounds, noise. Oh, taste. Everything. Oh he has keen keen eyesight. Hearing. He hears us talking. He hears us talking right now, oh yes. He's, you have to be very very careful if you say, if I'm talking on the phone and I don't want him to know, I'll go outside or in the bathroom and shut the door. If it's something I don't want him to hear, you just don't, never underestimate. (pause) He, the sensory stuff bothered him, but they're not as acute now as they were - or he's able to cope with them better, I think. . . . He's not as much, everything is lessening compared to what it used to be, that's for sure, but, um, he's

always been very anxious. But part of it is not knowing what's ahead of him. If he knows what's coming then that reduces the anxiety. (Katherine)

As with Katherine's statement above, other caregivers also articulated how anxiety, like sensory issues, affected their child(ren) and their learning in sexuality and beyond. For example, one caregiver likened anxiety to a fog that inhibited reasoning:

Nathalie: Would you say anxiety is also an obstacle?

Diane: Yeah, very, very big obstacle yeah. . . . Yes, if he's anxious, it's a bit like the anger, it's a bit of the same, a big fog, the reasoning stops and intaking stuff, he blocks. Yeah.

Another participant described how both anxiety and sensory issues impacted her child:

Nathalie : Est-ce que l'anxiété sociale est un obstacle pour votre enfant?

Denise : Oui, l'anxiété sociale, puis développer des liens avec les jeunes, des jeunes qui sont plus typiques et de son même groupe d'âge. . .

Nathalie : Est-ce qu'il a des besoins au niveau sensoriel?

Denise : Oui, [jeune], je pense que c'est plus comme son ouïe, chaque Asperger, chaque autiste a ses, au niveau sensoriel ils ont des choses où ils sont plus sensibles, lui c'est plus le bruit. C'est parce que en même temps aussi il est un peu comme doué au niveau de, euh, la musique puis comme il est très bon à jouer au piano à l'oreille. Mais je pense qu'il est facilement surchargé. Puis dans les classes aussi des fois quand il y a des groupes d'élèves bruyants.

Sensory issues and anxiety were perceived by caregivers as personal barriers for youth in accessing sexuality education or experiencing personal sexuality. In contrast, these and other issues were often also cited as personal strengths. In fact, an overwhelming majority of caregivers (10/11) described personal attributes as both strengths and needs for their child(ren), depending on the context. This points to the ambiguity and complexity inherent in describing an attribute from a qualitative and normative perspective. In summary, a small proportion of youth identified low self-perception as an obstacle to their sexuality more generally, as well as to their sexuality education. Caregivers did not identify this barrier, but did isolate sensory and related

issues as potential barriers. However, caregivers also perceived this attribute as a strength in certain contexts.

**Literalness and openness.** Although many caregivers identified literal thinking as a barrier, only one youth elicited this obstacle on his own. He articulated his challenge in this manner:

Misunderstanding, that's a big problem for me. Because I, sometimes, I listen to what the teachers say, but I won't understand exactly. It's just part of the problem with Asperger's. . . . It's just I find misunderstanding and being too literal is a big problem. . . . Because sometimes, some people don't take time to (turns to caregiver) I'm not saying you. No, it's other people. If they, if they don't know you don't understand it, they may not take the time to explain it to you, or take the time to say "This is what this, that means" or "I'm just kidding." Sometimes they have to see that you're kind of scared or confused to say "Oh, do you need help?" or "Oh, I was just kidding," like "Don't take it personally." I find that with me I kind of try to hide it. Instead of just talking it out, like I usually just hide the feelings. (Jeremiah)

Concrete thinking, exemplified above, had resulted in much misunderstanding, confusion, and emotional suffering. Again, while one youth named this obstacle, many more exhibited it.

Caregivers were generally more articulate about their child(ren)'s personal barriers. Most of the barriers elicited by youth were echoed and emphasized by caregivers. For example, literal thinking (10/11) was elicited as a barrier by the vast majority of caregivers. In describing literal thinking, caregivers explained that youth would tend to understand language in a very concrete manner, would fail to connect the conversation to its broader context, or would arrive at a superficial understanding of what was being discussed. This acted as a significant barrier to benefiting from sexuality education, especially in a school context. One caregiver explained how superficial understanding could present as a barrier when informally learning about sociosexuality from peers outside the classroom:

What kind of info are they getting from their friends, like is it true, you now? Because I've had [youth] come home and tell me that you know some of his friends talked about some sexual disease and he was afraid to get it. Because he didn't understand, right? That's what I mean about the literal stuff. It really puts a big barrier about what he can

understand and not, and he won't say that to his friends, right? Because you don't want to look stupid, you don't want to look like you're not part of the group. You'll laugh because they laugh, but you don't understand. So it's hard for them. You know. But, like I say, usually he'll come home and ask me. (Sandra)

Correspondingly, one couple discussed how understanding sarcasm was an important skill that was sometimes lacking for their youth, creating a social barrier between him and his peers:

France: Sometimes you wonder if he understands everything. Sometimes you tell him something and he says "Yes, yes" but sometimes you find out after that maybe he didn't fully understand, so I find that could be an obstacle. And um, like he will take some things very literally or obsessing on it.

John: I think in the past year, he's just starting to learn what sarcasm is, right? And, you know, he doesn't realize sometimes when you're teasing him, and he'll stop and ask you, you know, and so you have to be. And sometimes you're not sure if he's really grasping it. Sometimes he'll say yes, and then he'll just be lost. He didn't get it.

Many youth with high-functioning autism struggle with figurative and nonverbal language. As a result, they misunderstand or misinterpret important aspects of formal and informal sexuality education. Due to their intellectual ability, memory, and verbal skills, their limited understanding of sexuality may be masked. This "Aha!" moment became apparent during the transcription of one interview, early in the interview phase of my data collection, as illustrated in this journal entry:

I realized that, while I am speaking literally and explaining my affect to youth during interviews, I noticed that [some caregivers] used figurative language and sarcasm with [youth]. It seems they were sometimes using it on purpose to illustrate a point – [youth's] limited understanding. I almost did not catch that [youth] did not understand the joke made by [caregiver] because of his initial reaction. Listening to it again, it becomes clear. (Journal entry, January 15, 2013)

One example of how youth demonstrated limited understanding of subtle discussions about sexuality can be seen in the following exchange between a caregiver and her child where the caregiver related to me how an individual that both she and her child knew had a large penis:

Sandra: What I say you are going to think I'm a total nut. But [there] is size (laughs). I don't mean this to be funny, he could be a stripper. So they endowed him with, you know . . .

Youth: What do you mean by size?

Sandra: [Person] is hung.

Youth: What?

Sandra: [Person] is pretty – think of a horse.

Youth: Ha ha ha! I get it!

Sandra: Somebody who already has social problems, that can actually be . . .

Youth: What do you mean by a horse?

In this example, the youth did not understand the underlying meaning of the statements made by his caregiver, despite her various reformulations of the main point. The caregiver used the words “size”, “stripper”, “endowed”, then explained to her child that the person was “hung” and made an analogy to a “horse”, an animal whose physical attributes the youth was very familiar with, having grown up on a farm. The youth then went on to laugh and say that he “got” the joke, but this was quickly followed by the question “What do you mean by a horse?” which clearly demonstrated that he did not, in fact, “get it”. This is but one example of how youth showed limited understanding of topics related to sexuality education and its negative impact on benefiting from the curriculum, formal or informal, being provided to them.

Other caregivers explained how black and white thinking could cause problems with social relationships, especially if these relationships were ended by the other person. This concern was related to me by Diane:

Diane: But even in terms of just in life in general, like we've had, we had IBI [intensive behavioural intervention] therapists working here and you know when they quit and move on, he'd be devastated, just devastated. And you know, it doesn't take him long to get over it, but when it happens it's really shattering. And you know, until he gets over it, it concerns me. Stuff like that, they think the world is ending.

Nathalie: Do you think that it's related to the disorder? . . .

Diane: The black and white, yes I do. The not being able to see beyond the, it's like you know, you can study as many social stories as you want and you can discuss strategies when you feel a certain way, you're frustrated and you're angry or whatever doesn't mean you should do you know, strategies for coping whatever, all great, you can memorize them, tell them all, in the heat of the moment, yeah, it's just, it's this fog of reasoning (laughs).

Additionally, as was reviewed in Finding 5, openness toward the subject was seen as both a personal strength and a personal liability, depending on the context. In particular, openness was seen as a barrier in situations where others might not be as understanding or unaware of the traits associated with high-functioning autism. On this subject, a caregiver explained her child's openness was potentially useful for learning about sexuality education but could be misinterpreted, resulting in unintended negative consequences:

Nathalie: So you mentioned that children with autism ask questions that are often direct. Would you consider that a strength?

Diane: In certain contexts, but not if they get bullied for it afterwards. It's a bit of a catch 22, right? So, he might not understand that in certain contexts it's better not to be, you know, he'll often get picked on afterwards. . . . I think of adults who are not aware, they (youth with autism) can also look fairly rude, you know, that kind of thing. Which again he gets chastised as opposed to an answer. . . . Yeah, he's going to be more reticent to ask questions in the future because of it.

Thus, openness and concrete thinking were perceived as acting as both strengths and barriers for youth, depending on the context. In particular, these attributes were apt to cause problems for youth, specifically for sexuality in the presence of persons who were not aware or understanding of autism.

**Maturity.** A third barrier that was uniquely isolated by caregivers was that of maturity. Indeed, an overwhelming majority of caregivers identified maturity as an obstacle to sexuality education for their child(ren) (10/11). In particular, caregivers felt that their child(ren) experienced a developmental lag that acted as an obstacle to sexuality education. Because youth

were perceived as not developmentally mature enough for some topics of sexuality education currently provided in schools, some expressed the need to either adapt the curriculum or provide it at a different pace. This view can be seen in the excerpts below:

Um, when and how much? Much, when you look at him, when you compare him to other kids that age, they've already been exposed to it, and the question is "is he ready to be exposed to that?" because his grasp of that world is much more limited than most kids at that age. (John)

Ça fait son chemin, mais dans le fond là, tu sais, les autistes, ils font leur chemin à leur vitesse, à leur façon. Ça là le plus que je me renseigne sur l'autisme, c'est ça. Tu sais, on essaye, nous on voit ça, on voit leur vie, leur développement à travers de nos yeux de neurotypiques – ça marche pas. Tu sais ils sont ce qu'ils sont, puis ils vont développer à la vitesse qu'ils se développent. Puis c'est ça, c'est vraiment ça. Mais d'un autre côté, il faut être là aussi pour les outiller. (Lucie)

Therefore, maturity was seen as a personal obstacle when compared to children's neurotypical peers. However, lack of an adapted curriculum to address this difference was also identified as a barrier, as will be further discussed in the next and final finding.

**Summary.** Overall, caregivers were more able to identify personal barriers for their youth. In particular, they identified concrete thinking and openness as potential barriers. As with some youth, the majority of caregivers also identified sensory issues and anxiety as barriers to sexuality education and to sexual fulfillment. Not unimportantly, a third of youth identified low self-image as a personal obstacle to sexuality and sexuality education. Unique to caregivers was the identification of different rates of maturity as a barrier. Finally, it should be noted that most caregivers cited many personal attributes as playing the dual roles of barriers and strengths for their child(ren), depending on context. When viewed through a socially inclusive theoretical lens, these personal barriers can be categorized and better understood. Under scrutiny, it becomes clear that one personal barrier does not fit in a socially inclusive framework of impairment: low self-perception. All traits identified as personal barriers, except low self-perception, are directly linked with a diagnosis of autism: concrete thinking, openness, delayed developmental maturity,

and issues related to sensory perceptions. It is possible to conjecture that low self-perception is not actually a personal barrier, but is a consequence of a disabling environment. This may be true when juxtaposed with the external barriers of judgment and bullying identified through this study. Finally, as mentioned previously, some strengths and needs were viewed as interchangeable, depending on the context. This points to the need to revisit and refine the possibly incomplete theoretical framework developed for this study. The next and final finding discusses the social and societal barriers to sexuality education identified by youth and their caregivers.

**Finding 8: External barriers.**

*Overall, caregivers were more able to identify external barriers. Youth and caregivers both identified lack of friends/bullying as an obstacle. Caregivers also identified Internet/media, resource inadequacy, and judgment as barriers, whereas youth identified limited access to information as a barrier.*

Whereas the previous finding concentrated on internal barriers to sexuality education, this final finding focused on external barriers. External barriers included social and societal obstacles that were seen as hindering access to sexuality education for youth with high-functioning autism. A summary of the results obtained for this final finding are shown in Table 10.

**Lack of peers/bullying.** Consistent with other findings, youth enumerated fewer obstacles than did caregivers. As with the internal obstacles, a third of youth did not identify any external barriers that hindered access to sexuality education (3/9). Although there was no general consensus, most caregivers (9/11) and some youth (4/9) did identify lack of peers or bullying as a general social obstacle. One youth described how peers used his credulity to get him into trouble:

Some people in the past I've gone to they would tell me something false and if I repeated it, I got in trouble for it. . . . Like they knew I'd get in trouble. Like it was kind of a set up. . . . And then the principal would give me trouble. (Jeremiah)

Table 10  
*Summary of External Barriers Identified by Youth and Caregivers*

External barriers	Youth	Caregivers
SB—Overall	None identified (3/9)	—
SB1: Limited access to information	4/9	0/11
SB2: Lack of friends/bullying	4/9	9/11
SB3: Unmediated access to Internet and other media	0/9 <sup>a</sup>	10/11
SB4: Inadequate resources	0/9	9/11
SB5: Judgment	0/9	8/11

<sup>a</sup>Explicitly identified as support by some.

Another youth (Justin) described how changing schools was difficult, both in losing an established peer group, and in trying to create a new one. Bullying of a sexual nature was revealed as a problem in the youth and caregiver survey responses. Some types of bullying experienced by youth included being teased about their sexual orientation or about their body parts and having rumours spread about them. Half of youth reported having been called a mean name associated with their sexual orientation. Especially concerning was the finding that one youth reported having been forced by a peer to do something sexual other than kissing. As demonstrated above, youth described how lack of peers or bullying impacted them in a variety of ways, including their sexuality and their social learning.

Along with youth, the vast majority of caregivers also identified lack of peers and/or bullying as a barrier to sexuality education (9/11). This finding was for me the most poignant aspect of all interviews held with caregivers, none of which were as concisely illustrated as in Diane's response to my question on peer groups:

Nathalie: When it comes to his friends, do you think they would be a good source of information?

Diane: He doesn't have any friends.

In response to whether peers would be a good support for their child(ren), some caregivers described youth's experiences of bullying or other mistreatment by peers:

They were throwing pennies at him on the bus. Like they threw money at his face. And it came up before Christmas and we talked about it and I said "Well, people are gonna throw pennies," I said. "Well first of all you should ignore them because bullies will go away, usually. You try to ignore them first." So he said "OK." And I said "You know, I would like it if people threw money at me" and he said "Why would you like that?" and I said "Because I could save my money, I could take it home with me and make a piggy bank. We'll make a piggy bank and all the money they throw at you, we'll put in the piggy bank." So I never saw anything for a while, he seemed to be adapting. And Thursday I come home from work . . . and he's hanging his head and he's shuffling his feet and he won't make eye contact and his shoulders are hunched and you corner him and you're like "What's the matter?" and he's been holding it the whole time and he lifts up his hand and he has a handful of money that the children threw at him that day. And he just, that's all he does, he just holds it up like this (holds hand up, palm facing upward) and I'm just like "*Oh.*" (Nancy)

He thinks he has friends and I'm not sure, um, I guess he calls, um, like [peer X] his friend now and [peer X] is a very nice boy and he's been here, but sometimes he can be a real friend and sometimes "I don't know you" sort of idea, you know? And [peer Y] has always been a good friend when they're here, I don't know about when they're at school, because I know one of the [educational assistants] has said, because I always put down in the communication book that [peer Y] was here on the weekend and they did this this and this and then one of the [educational assistants] wrote . . . "You would never know that they were friends because [peer Y] doesn't play with him at school." (Katherine)

A caregiver explained that, in her view, youth with high-functioning autism were often desperate for social acceptance through friends or romantic partners. As a result, these youth could be easily manipulated into engaging in inappropriate behaviours by promising social benefits such as friendship in return. She described her view thusly:

The only time we ever see children, like [youth] can be manipulated into things, and that's because you've offered him something he thinks he should have. So if you offer him, you say "I will be your friend, because you need a friend" he's like "you're right I do." Because he's not stupid, he knows he doesn't have any. He knows he doesn't have friends, he knows how people react to him, he knows. So yeah, he should have a friend. And if you do certain things, he'll be your friend. Well the things he'll do to be your friend . . . Because he often doesn't pick up on the fact that a friend doesn't ask you to do these things. (Nancy)

This belief was also exemplified by France and John's description of an incident where their youth sought social approval by engaging in inappropriate behaviour:

France: He got himself in trouble with a girl, well the kids they teased him at school and they told him to tell another girl "Your titties are mine" and he went to say that to a girl and then she slapped him in the face. I was away on a [work-related] course. He [John] knows more.

John: I wasn't very happy with him. . . . Yes, he was grounded, and he was grounded from all electronics for the week, every day. That included TV. . . "You're not getting any electronics because that's unacceptable behaviour. [Youth], you don't go do something because someone tells you to do it." And for him, we have to be very careful with that, he knows right from wrong, but socially, his need to belong and to be accepted will lead him to do things that are not necessarily appropriate and he has to find his limits of . . . what he can do socially. . . . He knew something was seriously wrong because he came home and was trying to confess to me what he wanted me to hear before, because of course his sister found out and he wanted to make sure that he gets his side in there and then when it all came out, and I said "Well, [youth], what you're telling me doesn't even make sense." And he says "I don't even know what titties are." . . . He says "I didn't even know what titties are." He said "She smacked me and someone told me."

This situation personifies how lack of a supportive peer group and bullying work together to create a barrier to youth accessing meaningful informal sexuality education. The previous examples further demonstrate how no peer group and bullying affect youth more broadly as well, creating obstacles in all aspects of youths' lives.

Caregiver survey responses further corroborated sexual bullying as a concern for youth. Caregivers generally reported more bullying than youth, particularly in the areas of being called a mean name referencing sexual orientation (4/8), rumours being spread about them (3/8), and being subject to sexual jokes (3/8). There was one exception to this finding. One survey respondent commented that his daughter's school "is extremely and actively engaged in eradicating/controlling bullying at school . . . making sure that she is not subjected to such harassment" (caregiver survey participant). Notwithstanding this exception, the above findings demonstrate that lack of a peer group and bullying act as barriers to sexuality education and healthy sexual development and expression, according to youth and caregivers.

**Limited access to information.** Along with bullying, limited access to information was the most commonly cited external barrier according to youth (4/9). One young participant said information was often withheld by parents who were overly protective of their children. He explained:

Jason: People can be too, what's the term, protective of kids nowadays. I uh, I admit, I spend a lot of time on the Internet, and there's some parts I don't exactly want kids to find out about. Yeah, it's nuts. But . . . sometimes it seems that they (parents) are going overboard. . . . Yeah, I think on the subject of sex ed, going by their logic, I'm pretty sure that they want to keep them away, keep kids away from it, it would seem illogical, but they want to keep it away from their kids as long as possible.

( . . . )

Nathalie: Do you think parents should be a little less protective?

Jason: Well, not protective, but they gotta be able to explain it to their kids.

In this sense, participants felt that their caregivers should provide them with the sexual information they needed to grow up in a healthful manner. Relatedly, some youth described that information needed to be concrete and detailed, and needed to come from various sources. This was exemplified in the statement below:

At school, sometimes I would misunderstand [sexuality education], and sometimes it was not as detailed. Except the teachers have more than one student to teach, they don't have time to go through every student's questions. So it's not as explained for most students, so parents I find they have more time to speak to their students. (Jeremiah)

Another participant echoed this sentiment:

Steve: The biggest thing for me is probably how I would have trouble getting in the relationship in the first place. Be it a lack of confidence or a lack of information on how to. Because both of those with me it's a big question mark, really. And I'm certain that it's probably the same way with a lot of other kids with autism and such.

Nathalie: Why do you think that is?

Steve: It's probably just because maybe it's because people don't think it's a problem off hand unless they're told it by someone with autism. And maybe it's just because they figure it's sort of natural really, or if not, that it's sort of a thing that you can pick up as you go along.

This need for explicit and precise information was related to their autism profile. This point relates back to and echoes caregivers' view expressed in Finding 1 in that the person responsible for providing sexuality education requires a good handle on the youth's profile to be effective. Hence, limited access to information acted as a barrier, according to youth.

**Internet and other media.** Although youth were limited in their ability to articulate external barriers to sexuality education, caregivers were not. Indeed, whereas youth had identified the Internet as a potential support in Finding 6, the vast majority of caregivers (10/11) clearly viewed the Internet and other media as potential or actual barriers, when these were used without contextualization or mediation. Of particular concern to caregivers was their children's unmediated exposure to manufactured sexual situations in various media that may be misinterpreted as reality and the impact on their behaviours or perceptions. Such apprehension was clearly articulated by these caregivers:

And so, it's on our video games! You play a video game, like everyone was laughing at me because I don't play video games and I got some game and I think it was Halo and I read on it and it looked OK, and it looked normal and then [youth] comes upstairs and he says to me something about can I watch him play the game and I say "Sure, I'll watch you play the game" and I go down and I'm so lost and bored too, I really don't like games. Well, he's telling about the game and I realize I have to take the game away. I just bought it and I have to take it back because in this game . . . I think it's like a role playing game where you go and you find things and you can find condoms and you should keep those because when you have sex with prostitutes you don't want to get them pregnant and when you find the one you're going to love, then you don't need the condoms anymore. And he's explaining that you need the condoms to protect yourself from STDs and pregnancy and it's amazing! (Nancy)

Mais aussi penser, comme, pour moi, c'est un peu dans toutes mes matières que, y'a comme une culture dominante qui est plus à l'extérieur, puis dans le monde scolaire ou dans l'éducation à la sexualité, c'est un peu comme le monde idéal parfois, et que, il y a beaucoup de pression sur les jeunes qui vient de l'extérieur de l'école ou sur L'Internet, et vraiment maintenant ils ont accès à beaucoup de choses puis c'est pour ça que je pense qu'il serait bon de le commencer jeune. Puis de parler des choses comme la pornographie et de choses comme ça. . . . Je pense que ça serait bien d'être comme dans certaines classes tu sais de dire « voici ça, qu'est-ce que ça représente, puis comme ça ne représente pas nécessairement la réalité. » (Denise)

Yes. Especially the X Box, the videogames, the, the denigration of women, that kind of thing. Some of them are pretty degrading to women. . . and the repartee (laughs) leaves a little to be desired. Let's put it that way. So I'm not too thrilled with some of them, the videogames and stuff. Yeah. And it's also on TV as well, but he doesn't watch that much TV, but he will watch a lot of You Tube and again there, you get a lot of it on You Tube. (Diane)

Caregivers were concerned with youth exposure to sexuality in videogames, television, the Internet, and other media and technology. Similarly, one couple related their concern when their young teenager had accessed the Internet in search of a girlfriend and the broader implications of the intersections between sexuality and technology for youth with autism:

John: Just a little while ago, it was on Facebook.

France: We caught him going to a dating website.

John: That comes off his Facebook page. Zoosk. Of course now his access is not guarded, but we have his passwords, we have total access. So we can go in and track his history and what he's doing and he put in that he's interested. So his sister looked and said that "You know that [youth] is looking at Zoosk?" and I said "[Youth] you can't go on those websites!" "But I really want a girlfriend and I thought I could get one there." "But it doesn't work that way". . . . The Internet is full of porn and it sometimes can lead them to the wrong idea, like this is how we sexually interact. Because it's such a huge component on there and it's so hard to block all of it and it may be, sorry, I can put all the parental controls on this, guaranteed two of his friends have iPhones, that's walking Internet. I can't control that.

France: He'll go to a friend. He'll go see a friend that doesn't have parental control.

Caregivers acknowledged the conundrum of the Internet as something that was necessarily present in the lives of youth but was problematic when used without adult supervision or support to contextualize the information and images being accessed. The difficulty in knowing which sexual media content youth accessed when they were not present was reflected in the survey findings as well. Regarding whether their child had viewed online pornography, some (3/8) responded that they *don't know* (2/8 responded *sometimes*; 3/8 responded *never*).

Thus, various forms of media (e.g., Internet, television, movies, and video games) and technology (handheld devices, tablets, phones, laptops, computers, and game systems) were viewed as external barriers when their use was unmediated and lacked contextualization. Caregivers also discussed their necessary inclusion in the lives of their children, acknowledging the benefits of media and technology to enhance their lives as well. Nonetheless, caregivers expressed powerlessness in their ability to control or limit access to these items both inside and outside the home.

**Lack of/Inadequate resources.** One barrier only identified by caregivers was that of inadequate resources. The vast majority of caregivers identified unresponsive or inadequate resources for their family's unique situation as a barrier to accessing sexuality education (9/11). One caregiver described the need for sexuality education for youth who were otherwise excluded from a classroom setting because of needs related to their disorder:

A child has a right to go to school in Ontario. This didn't happen in [youth]'s case and I had to take two months off work and tackle these guys head to head to get him what he should have had by right. So the school boards have a bigger stick and they decide who and who doesn't go, who gets into the bell curve, who doesn't. But with kids who don't fit into the bell curve, it would be nice to see nurses come in to the home maybe and have a chat and make sure that that part of the education isn't lost because, I mean, we're open about sex in our home, um, not all homes are, and in some homes they think kids wouldn't even hear about this stuff. They just hear about porn on the Internet, I don't know. So I think it would be nice if there was back fill because I know the hospitals and schools are, you know, very separate entities, very separate philosophies, so. (Ronan)

In this instance, Ronan expressed the need for resources that were responsive to a family's reality. Similarly, according to another caregiver, current provision of sexuality education in school did not meet her child's needs:

I think the school does the absolute minimal amount (laughs). I think they do what they're mandated to, I don't think they do it all that effectively, necessarily. I'm a little disappointed in the scope and reach of what they do. It seems to be done very quickly and then we package it up until next year, we don't have to talk about it anymore, you know? (Diane)

The lack of adequate access to appropriate sexuality education acted as a barrier to youth, according to the caregivers quoted above.

Additionally, although all caregivers reported having used at least some forms of resource materials (e.g., books and pamphlets), most caregivers were not aware of sexuality-based educational resources specific to the learning particularities associated with high-functioning autism. As one caregiver explained, she perceived a lack of adapted resources specific to teaching sexuality education for her child with autism:

But like I said there's no literature. They'll tell you to tell your children, and you can read all the books you want, I remember reading all of them with [daughter] and they'll tell you that you can tell your kids *this*, and this is how you should explain *that*, and these are the guidelines you should use. But no one ever tells you how to tell someone who processes information different. (Nancy)

Only one caregiver (Katherine) reported having used a sexuality resource specific to high-functioning autism/Asperger syndrome (Attwood, 2008). One caregiver (Lucie) had attended a workshop on sexuality for youth with high-functioning autism/Asperger syndrome presented by Hénault. This caregiver (Lucie), along with one other (Denise), reported they had enrolled their child in an upcoming community-based sexuality education course based on Hénault's (2006) curriculum. Thus, caregivers displayed varying degrees of awareness and use of autism-specific sexuality resources, with most caregivers indicating having limited knowledge of resources available. Moreover, caregivers gave a number of examples of unresponsive or lacking resources acting as barriers to sexuality education for youth with high-functioning autism on several levels.

**Judgment.** Over half of caregivers identified judgment by others as an obstacle to sexuality education for their child(ren) (8/11). Some caregivers explained that their child(ren) had somewhat of an invisible disability in the sense that their autism was not always immediately

apparent in the way a physical disability may be. As a result, these children were often judged for being different. As one caregiver described her child's so-called "invisible disability":

It's a huge obstacle, it's a huge invisible until it's visible and then it's judged. . . . Like it's completely – don't see it, don't see it, "Oh my God" now you see it then you're like "What did his parents do? What is wrong with that kid?!". It goes from invisible to visible – judged. Done. (Nancy)

Likewise, one caregiver described how her child had been judged in the past for being different and laid out her fears and hopes about the future:

People really have no clue. They have no clue if someone has a meltdown in public. They just think "Oh." Especially with a child, you know, that it's just a bad kid. Well, not necessarily. You know, you have no clue. It could be because the child is autistic or whatever. And I'm sure that will come into play later too, but hopefully you know you hope that they'll find a girl that will be able to get past those things and work with them and you know. But yeah, for sure, definitely how people perceive. 'Cause that would minimize who or what he's able to be with, I would assume, unfortunately because people are very judgmental.

Similarly, another caregiver, Lucie, commented that others had judged her child for being different, stating « dans le fond l'obstacle c'était, c'est les yeux des autres, dans le fin fond, c'est ça que c'est. Le jugement des autres. » Yet another caregiver, recognizing that many people judged her child, described the importance for him to seek peers who would accept him for who he was. On this topic, the caregiver provided the following comment:

C'est un obstacle et un soutien en même temps. Je pense que ça va être plus pour lui comme de trouver des gens qui vont l'accepter comme il est puis en même temps qui ont un peu une approche un peu plus progressive de la sexualité ou de un peu de la justice sociale aussi là-dedans je sais que c'est important pour [jeune]. (Denise)

Hence, many ascertained that judgment by others was an obstacle to their child's access to sexuality education, but also, and perhaps more importantly, to being accepted socially and thereby benefiting from sexuality education more broadly.

## **Summary.**

To summarize, caregivers were better able to articulate barriers to sexuality education than youth. A third of youth felt that there were no obstacles to accessing sexuality education. Of those youth who did identify external barriers, the most common barriers were lack of peers or bullying. Lack of peers or bullying were obstacles identified by the majority of caregivers. Additionally, youth cited lack of relevant information as a potential barrier to sexuality education. Caregivers, in contrast, cited unmediated access to media and technology as a major barrier to appropriate sexuality education for their child(ren). They also noted inadequate and/or unresponsive resources, as well as judgment by others as social and societal barriers to sexuality education.

Examined through a lens of social inclusion, these barriers are in step with the rest of the findings of this study. Lack of peers and bullying, mapped onto the framework, can be contrasted with positive peer relations, which act as a support. The effects of bullying and judgment can create the disabling effect of low self-perception. As mentioned previously, this negative self-perception may be understood as necessarily residing in the individual; it can be assumed to be part of the impairment of autism. However, as it is not part of the diagnostic criteria, it seems more plausible that it is a consequence of environmental barriers. Inadequate resources and lack of information can be understood as going hand in hand, and can be seen as acting as barriers to meaningful sexuality education. This would make sense in light of the definition of sexuality education proposed by youth and caregivers in this study who indicated the need for factual information.

The Internet was seen as both a support and a barrier. According to caregivers, it was the unmediated/uncontextualized use of the Internet and other media/technology that acted as a barrier. Again, this view is concordant with the definition of sexuality education proposed

previously, which identified the need for information and skills. Potentially, part of the skill set required may involve safe (and critical) use of media and other technology. These points are explored in further detail in the proceeding chapters.

**Summary of findings related to Research Question 1.** The first research question looked at what sexuality education means for youth with high-functioning autism and their caregivers. To answer this question, sexuality education was broken down according to its form (understood as responsibility, educator qualities, and provision) and goals (understood as content). Regarding form, youth and caregivers agreed on presentation, responsibility, and the quality of the educator, whereas they disagreed on the priority of responsibility, educator qualities, and gender grouping. An overwhelming majority of youth and caregivers thought caregivers and schools should be primary providers of sexuality education. Most caregivers identified community partners as also responsible for providing sexuality education, whereas only one youth did. With very few exceptions, peers were generally not perceived as being good educators across all informants. Both youth and caregivers cited that educator qualities impacted the quality of sexuality education. Although youth stressed the importance of educators' personal traits and relevant knowledge and experience, caregivers placed more emphasis on educators' knowledge of autism, trustworthiness, and alignment with family goals.

Regarding provision, all youth and a vast majority of caregivers believed that sexuality education should be provided as 1:1 or group-based delivery. On the issue of gender groupings, the majority of youth did not have a preference between mixed or segregated gender groupings, whereas an overwhelming majority of caregivers believed that sexuality education should be provided either partly or fully segregated by gender. For timing of provision, a majority of caregivers believed that sexuality education should be provided according to the physical and

developmental maturity of the child. Thus, sexuality curricula may need to be adapted to meet the needs of various individuals.

Another dimension of sexuality education explored as part of this study was that of content. Specifically, this analysis considered what should be included and excluded as part of a sexuality education curriculum. A vast majority of youth wanted to learn specific sociosexual behavioural rules and timelines. Similarly, though more broadly stated, all caregivers affirmed that contextualization of information through explicit teaching of social/sexual behaviours and conventions were central components to a sexuality curriculum. A related finding was that an overwhelming majority of parents wanted to normalize their child(ren)'s sexuality through sexuality education. Youth and caregivers related the importance of presenting facts in a sexuality curriculum. Caregivers associated teaching about facts with safety, as did some youth. Pleasure was a less-common theme, explicitly discussed by two youth and two caregivers, though the theme was implicit in discussions with other caregivers. Specifically, pleasure was linked to discourses of normalized sexuality for individuals with autism.

A finding that emerged from all caregivers but not from youth was that sexuality education should transcend discrete classroom boundaries. Caregivers brought up critical incidents where new behaviours or situations occurred related to their child's sexual/social development indicating a need for prompt, informal sociosexual education for their child(ren). Many caregivers acknowledged feeling uncomfortable or ill-prepared to respond to the incidents. Nonetheless, the vast majority of caregivers who shared critical incidents used them as teachable moments to discuss sexuality with their child(ren).

**Answering Research Question 1.** Thus, to answer Research Question 1, sexuality education was conceptualized by youth and caregivers as a curriculum that encompasses

behavioural norms, facts, and to a lesser degree, pleasure. No topics were identified as taboo by youth or caregivers. Youth also conceived of sexuality education as including rules and timelines. Caregivers understood sexuality education to be teaching contextualized information and behaviours, and also focusing on normalizing views toward the sexuality of their child(ren). Youth and caregivers both understood sexuality education as being the responsibility of caregivers and schools, with caregivers also identifying the role of community partners. Educators require trustworthiness, relevant knowledge, and experience related to sexuality education (youth) or youths' autism profiles (caregivers). Youth and caregivers conceived of sexuality education as taking place as a mix of 1:1 and group-based delivery. Youth also understood sexuality education to take place in mixed-gender groupings, whereas caregivers saw it being delivered as partly or fully segregated by gender. Caregivers understood sexuality education as adapted to the developmental level of their child(ren). Finally, caregivers conceptualized sexuality education as a mix of formal and informal activities that took place across multiple settings over time.

**Summary of findings related to Research Question 3.** The first three findings centred on answering Research Question 1 by defining sexuality education according to youth and caregiver perspectives. The last four findings focused on identifying the supports and barriers to accessing sexuality education to answer Research Question 3. The third research question centred on identifying the personal strengths, external supports, and personal and external barriers to sexuality education. Findings 5 and 6 explored personal strengths and external supports, whereas Findings 7 and 8 reviewed personal and social/societal barriers.

Although an overwhelming majority of youth displayed personal strengths (during interviews or as described by caregivers), many youth struggled to identify personal strengths

related to sexuality education. All youth, however, were able to identify more concrete attributes. All caregivers were able to identify a number of personal strengths for their child(ren) related to sexuality education, including intelligence and affective empathy. Some attributes were seen as both strengths and challenges, depending on context. For example, most caregivers identified openness/interest toward the subject as a personal attribute, whereas most of them also saw this attribute as a potential barrier. Likewise, some caregivers identified concrete thinking as a strength related to sexuality education, whereas an overwhelming majority of caregivers viewed this attribute as a potential barrier.

Regarding external supports, both youth and caregivers identified caregivers and other trusted adults as advocates in accessing sexuality education. Youth and caregivers differed regarding the Internet and other media. Youth identified the Internet and other media as potential resources, although this view was with reservations for many youth. Caregivers, in contrast, perceived the Internet and other media as potential barriers. A third of youth and just under half of caregivers identified peers as good resources, when these peers were available.

The final two findings were concerned with personal and social/societal barriers to sexuality education for youth with high-functioning autism. As with supports, caregivers were generally better able to identify personal and social barriers for youth than youth could. All caregivers identified barriers for their child(ren), whereas a third of youth did not perceive any personal obstacles that would prevent them from accessing sexuality education. Caregivers identified various forms of literal thinking as a major barrier, whereas only one youth did. Associated with the previous finding on adapted curriculum provision, youths' delayed developmental maturity was viewed as a barrier by the vast majority of caregivers. Sensory issues, anxiety, and/or attention were identified as personal barriers by most caregivers, but only

a third of youth. One personal barrier that was identified by a third of youth but not by their caregivers was that of negative self-image and/or low levels of confidence. However, understood through a socially inclusive framework, it would appear that this barrier may be a symptom of an external barrier rather than a true personal impairment.

Concerning external barriers, many more social and societal barriers were named by caregivers than by youth. Almost half of youth and most caregivers identified lack of friends or bullying as obstacles, with consequences that extended beyond the realm of sexuality education. Caregivers also identified unmediated access to media and technology (particularly the Internet) as a barrier to appropriate sexuality education. In contrast, youth identified limited access to information as a barrier. Caregivers also mentioned resource inadequacy and judgment by others as barriers to sexuality education.

**Answering Research Question 3.** Hence, to answer Research Question 3, caregivers identified openness, intelligence, empathy, and concrete thinking as strengths in supporting their sexuality education. Youth and caregivers named trusted adults as central external supports, and peers to a lesser extent. Youth also classified the Internet as a potential support. Caregivers and youth listed sensory and related issues as personal barriers. Youth also pinpointed low self-perception as a barrier. Caregivers enumerated maturity, concrete thinking, and openness as potential barriers as well. Youth and caregivers identified lack of peers and bullying as external barriers. Youth also enumerated limited access to information as a barrier, whereas caregivers noted Internet and other media, inadequate resources, and judgment as barriers to sexuality education. Finally, caregivers qualified personal strengths and personal barriers as being interchangeable attributes depending on their context.

## **Chapter Summary**

This chapter presented the eight major findings discovered in this research project, and discussed seven of these findings in depth. These findings were presented according to two (Research Questions 1 and 3) of the three research questions that guided this study. The first three findings sought to conceptualize sexuality education from youth and caregiver perspectives. Sexuality education was defined according to its form and purpose. Specifically, the first finding looked at the modalities of sexuality education, while the second finding examined its content. The third finding touched on both form and purpose. Following their presentation, the seven findings were used to answer Research Questions 1 and 3. Having presently answered these questions, I now turn to Finding 4, which attempts to answer Research Question 2 of this thesis. It provides evidence from relevant literature, policy documents, and curricula in support of the conceptualizations of sexuality education presented in the first three findings answering Research Question 1 in this chapter.

## CHAPTER 6: TEXTUAL FINDINGS AND ANALYSIS

### Introduction

The purpose of the first research question was to provide a conceptualization of sexuality education from an emic perspective. Correspondingly, the first three findings provided a definition of sexuality education, as conceptualized by youth with high-functioning autism and their caregivers. The purpose of the second research question was to see in what ways various textual sources in the field of sexuality, education, and autism supported or qualified the findings associated with Research Question 1. Thus, this portion of the study provides the second phase of the literature review. The initial literature review provided in Chapter 2 addressed prior research on the sexuality/sexuality education of individuals with autism. The primary purpose of that review was to compare existing research according to certain dimensions (e.g., methodology, subject, and intervention). In this manner, it sought to identify gaps and situate the current study in its historical context. It also considered barriers impeding sexuality education for individuals with autism, thereby providing context for the third research question of this study. The current phase of the literature review specifically addresses the areas of sexuality education form and content, and does so from research, policy, and practice perspectives. Here, I seek to answer the question, How do extant texts inform the conceptualizations of sexuality education obtained in Research Question 1? To answer this question, I reexamined the literature reviewed in Chapter 2, as well as other practical and theoretical literature related to sexuality education and disability. In addition to this, relevant policy documents, curricula, and resources were explored.

As discussed in the initial literature review, the needs of youth with high-functioning autism with regards to sexuality education are different from those of youth with other developmental disabilities (including other individuals with autism), as well as neurotypical

youth. In light of this, the focus of the policy and curriculum examination for this research question was limited to this study's target population to the extent possible. Because no policy was found specifically relating to sexuality education for high-functioning autism, more general policy documents were used to support the findings. Prior to reviewing Finding 4, I provide contextual information regarding some of the policies and curricula retained to answer Research Question 2.

**Overview of policies and curricula.** Currently in Canada, federal guidelines established through PHAC (2008) are in place regarding sexual health education. According to PHAC, these guidelines are designed to assist in the development and implementation of sexual-health programs, provide a framework to evaluate programs, policies, and services, and provide a better understanding of the aims of a broadly based sexual-health education; they do not provide specific curricula or teaching strategies (PHAC, 2008). In addition to PHAC's sexual-health guidelines, other relevant policy documents were retained that addressed sexuality education. In particular, the *Guidelines for Comprehensive Sexuality Education* created by SIECUS in 2004 (p. 5) are viewed as a centerpiece of sound sexuality education policy. Additionally, recent policy put forth by the Sex Information and Education Council of Canada (SIECCAN) (McKay & Bissell, 2010) was included for its relevance to the Canadian context of sexuality education.

In addition to Canadian federal guidelines, sexuality curriculum standards are in place at a provincial level. In Ontario, sexuality education currently falls under the *Health and Physical Education Curriculum* at the elementary level (MEDU, 2010a, 2010b; previously *Health and Physical Education Curriculum: Healthy Living*, MEDU, 1998/2005) and *Healthy Living & Healthy Growth and Sexuality* at the secondary level (MEDU, 1999). A few years ago, the government of Ontario completed a 2-year revision process to update the curricula for Grades 1

to 8. The process involved an analysis of the current curricula, an international examination of evidence and best practices, and focus-group consultations with various stakeholders, including education and health experts, caregivers, students, educators, and cultural/religious groups (Ophea, 2010). The Ontario government introduced the new sexuality curriculum in January of 2010. Shortly thereafter the curriculum was withdrawn due to opposition from certain interest groups (CBC, 2010; Ophea, 2010), despite strong support for the revised curriculum by over 770 stakeholders and organizations (Ophea, 2010). Indeed, most Canadians have long supported broad-based sexuality education (e.g., Di Giulio, 2003; Herold & Benson, 1979; Marsman & Herold, 1986, McKay et al., 1998). Currently, the provincial government has stated its intention to review the parked curriculum with various stakeholders and reimplement it provincewide, however this has not yet taken place (Pearson, 2013). In the meantime (2010 to the present), an interim revised version of the 1998/2005 curriculum is in use in schools at the elementary level, whereas the 1999 and 2000 editions of health education continue to be used at the secondary level (MEDU, 1999, 2000; Pearson, 2013). A complete summary of the curricular expectations and goals related to sexuality included in the *2010 Health and Physical Education Curriculum: Grades 1 to 8* can be found in Appendix X (MEDU, 2010a, 2010b; People for Education, 2013). Both the unedited and revised contents are included in Appendix X. I included a summary of the curricular expectations and goals related to sexuality in the *1999 Healthy Living & Healthy Growth and Sexuality: Grades 9–12* (see Appendix Y; MEDU, 1999, 2000).

Youth participants included as part of this study were between the ages of 12.5 and 17. Accordingly, they attended school between the grades of 7 and 12. To help contextualize the information from various sources, Table 11 highlights the current Ontario sexuality curriculum content specific to these grades.

Table 11

*Summary of content areas from current Ontario curriculum, Grades 7–12*

---

GROWTH AND DEVELOPMENT – Interim Edition (MEDU, 1998/2005, 2010b)

Grade 7 (p. 184)

SPECIFIC EXPECTATIONS

- explain the male and female reproductive systems as they relate to fertilization;
  - distinguish between the facts and myths associated with menstruation, spermatogenesis, and fertilization;
  - identify the methods of transmission and the symptoms of sexually transmitted diseases (STDs), and ways to prevent them;
  - use effective communication skills (e.g., refusal skills, active listening) to deal with various relationships and situations;
  - explain the term *abstinence* as it applies to healthy sexuality;
  - identify sources of support with regard to issues related to healthy sexuality (e.g., parents/guardians, doctors).
- 

GROWTH AND DEVELOPMENT – Interim Edition (MEDU, 1998/2005, 2010b)

Grade 8 (p. 201)

SPECIFIC EXPECTATIONS

- explain the importance of abstinence as a positive choice for adolescents;
  - identify symptoms, methods of transmission, prevention, and high-risk behaviours related to common STDs, HIV, and AIDS;
  - identify methods used to prevent pregnancy;
  - apply living skills (e.g., decision making, assertiveness, and refusal skills) in making informed decisions, and analyze the consequences of engaging in sexual activities and using drugs;
  - identify sources of support (e.g., parents/guardians, doctors) related to healthy sexuality issues.
-

---

Grade 9 (p. 10)

SPECIFIC EXPECTATIONS

- identify the developmental stages of sexuality throughout life;
  - describe the factors that lead to responsible sexual relationships;
  - describe the relative effectiveness of methods of preventing pregnancies and sexually transmitted diseases (e.g., abstinence, condoms, oral contraceptives);
  - demonstrate understanding of how to use decision making and assertiveness skills effectively to promote healthy sexuality (e.g., healthy human relationships, avoiding unwanted pregnancies and STDs such as HIV/AIDS);
  - demonstrate understanding of the pressures on teens to be sexually active;
  - identify community support services related to sexual health concerns.
- 

Grade 10 (p. 15)

SPECIFIC EXPECTATIONS

- describe environmental influences on sexuality (e.g., cultural, social, and media influences);
  - explain the effects (e.g., STDs, HIV/AIDS) of choices related to sexual intimacy (e.g., abstinence, using birth control);
  - identify available information and support services related to sexual health concerns;
  - demonstrate understanding of how to use decision-making skills effectively to support choices related to responsible sexuality.
- 

Grade 11 (p. 11)

SPECIFIC EXPECTATIONS

- describe factors (e.g., environmental, hormonal, nutritional) affecting reproductive health in males and females;
  - demonstrate an understanding of causes and issues related to infertility;
  - demonstrate the skills needed to sustain honest, respectful, and responsible relationships;
  - describe sources of information on and services related to sexual and reproductive health;
  - assess reproductive and sexual health care information and services.
-

**SPECIFIC EXPECTATIONS**

- analyze the factors (e.g., culture, media) that affect gender roles and sexuality;
  - demonstrate an understanding of the factors (e.g., attitudes, values, and beliefs about gender roles and sexuality) that affect the prevention of behaviour related to STDs, AIDS, and pregnancy;
  - describe the factors (e.g., healthful eating, abstinence from smoking and alcohol) that contribute to healthy pregnancy and birth;
  - describe the characteristics of healthy, respectful, and long-lasting relationships;
  - assess the skills needed to maintain healthy, respectful, and long-lasting relationships;
  - describe the communication skills needed to discuss sexual intimacy and sexuality in a relationship.
- 

Although I included the provincial curriculum documents listed in Table 11 under the “Curricula” heading in Tables U1, V1, W1 in Appendices U, V, and W, I recognize that such documents act in dual capacities. They are curriculum documents in that they describe the specific content areas covered as part of health and physical education in schools in Ontario. They are also policy documents that indicate courses of action by identifying what is and what is not to be taught in schools in Ontario. These documents are therefore treated as both policy and curricula in my analysis.

Regarding sexuality curricula specific to youth with high-functioning autism, only two curricula were found that met these criteria. The first was Davies and Dubie’s (2012) relationship and sexual-health curriculum for individuals with high-functioning autism. The second was Hénault’s (2006) sexuality curriculum for individuals with Asperger syndrome. The former curriculum is targeted for adolescents and is meant to be taught in a group setting by a sexuality educator, though it can be adapted to be taught individually by a caregiver or therapist (Davies & Dubie, 2012). The latter is targeted to adolescents and adults and is also meant to be taught by an

educator and in a group setting (Hénault, 2006). Neither of these curricula contains a caregiver-education component. Having provided a brief overview of key sources of policy and curriculum, I now turn to Finding 4 which addresses Research Question 2.

**Research Question 2:**

*How do prior literature, policy, and curricula in this field inform this definition?*

Pursuing the line of thought employed to answer the first research question, the same two dimensions of sexuality education were considered: form and content. As a result, Finding 4 addresses both of these dimensions by supporting textual evidence.

**Finding 4: Extant textual evidence.**

*Generally, the sexuality education definitions provided by youth and caregivers were well-supported across the literature and curricula. No policies were found that pertained specifically to high-functioning autism and sexuality education; however, broader policies on sexuality education did support the definitions, albeit to a lesser extent.*

**Form.** The proceeding section describes textual evidence for the form of sexuality education according to facets of responsibility, educator qualities, and provision. To assist in the visualization of the results and supporting evidence, Table U1 illustrates the various dimensions of sexuality education, as defined by youth and caregivers, and as informed by recent relevant literature, policy, and curricula/resources (see Appendix U).

**Responsibility.** Overall, text sources supported the view that sexuality education is the primary responsibility of caregivers, and should be supported by other professionals such as schools, medical organizations, and community partners. A common thread was the shared role of caregivers and schools in providing appropriate education, with an emphasis on the family to provide the values inherent in any sexuality education. This view was discussed at a more general level by SIECCAN, stating,

parents and guardians are an important and primary source of guidance for young people concerning sexual behaviour and values. . . . Parents also recognize that schools should play a key role in the sexual health education of their children. (McKay & Bissell, 2010, p. 5)

Along these same lines, the focus on a home–school partnership with families as a source of value-based education was also emphasized by the MEDU:

Parents are the primary educators of their children with respect to learning about values, appropriate behaviour, and ethnocultural, spiritual, and personal beliefs and traditions, and they act as significant role models for their children. It is therefore important for schools and parents to work together to ensure that home and school provide a mutually supportive framework for young people’s education. (2010a, 2010b, p. 10)

The value of schools as formal environments where sexuality education can occur for every student was emphasized by PHAC:

Schools are one of the key organizations for providing sexual health education. They can be a major pathway to ensure that youth have access to effective and inclusive sexual health education. Since schools are the only formal educational institution to have meaningful (and mandatory) contact with nearly every young person, they are in a unique position to provide children, adolescents and young adults with the knowledge, understanding, skills and attitudes they will need to make and act upon decisions that promote sexual health throughout their lives. (2008, p. 19)

In this way, schools can ensure sexuality education occurs for youth who may not access it from home or in more informal ways, such as through peers, as is often the case for youth with autism (Stokes et al., 2007; Volkmar & Wiesner, 2003).

Along with home and school, community partners were emphasized as potential sources of sexuality education. Among cited partners were community recreation facilities, social service agencies, universities and colleges, businesses (MEDU, 2010a; 2010b), cultural organizations, and religious leaders (SIECUS, 2004). Many authors also emphasized the role of health care professionals such as nurse practitioners (Chan & John, 2012; Davies & Dubie, 2012), pediatricians (Murphy & Roy Elias, 2006), and other related specialists (Hénault, 2006; McKay & Bissell, 2010; MEDU, 2010a, 2010b). Such specialists could provide expertise in areas that

may be less familiar to educational staff and caregivers (MEDU, 2010a, 2010b). Some sources supported the view that peers could act as appropriate educators (Nichols et al., 2009; MEDU, 2010a, 2010b; PHAC, 2008; Wolfe, Condo, & Hardaway, 2009). These roles, however, were generally qualified. For example, Nichols et al. (2009) described the role of peers as pertinent when teaching social skills related to sexuality. PHAC described the role of peer-educators in the following way:

Effective sexual health education encourages and strengthens the role of peer education and support. Individuals involved in peer education should be well-trained, carefully supervised and be aware of the differences between this type of supportive role and professional counselling or therapy. (2008, p. 25)

From a research perspective, Stokes et al. (2007) recognized that, although beneficial in theory, in practice individuals with high-functioning autism may not be able to benefit from peer teaching in the ways intended by policies and curricula created for the general population because of the social and communicative deficits associated with their disorder. From a practical perspective, one psychologist viewed peers as unreliable sources of information and potential exploiters of youth with autism (Moxon, in Middletown Centre for Autism, n.d.). It would seem that peers may not be appropriate formal educators, but could potentially provide a supportive role.

One source, the MEDU (2010a, 2010b), recognized the importance of youth taking responsibility for their own sexuality education. Indeed, the MEDU explained that students gradually become increasingly responsible for their own learning as they mature. The view that youth should self-teach sexuality education was not supported in other textual sources. Indeed, arguments against this approach were put forth by some because impairments related to high-functioning autism affect areas of self-knowledge (e.g., Hatton & Tector, 2010; Mehzabin & Stokes, 2011; Mitchell & O'Keefe, 2008; Roth, 2009). Self-advocacy, however, was supported

in the literature (Aylott, 2000; Blanchett & Wolfe, 2002; Hingsburger & Tough, 2002; Tarnai & Wolfe, 2008; Wolfe et al., 2009). Self-advocacy skills can be understood as potential personal strengths to access sexuality education that could not otherwise be accessed on an individual basis because of the nature of impairments related to autism.

Overall, then, the literature supported caregivers as primary providers, with schools, other professionals, and community organizations sharing the responsibility of provision. A few sources supported peers as potential educators, though their role was more supportive than educative. Some sources emphasized the dimension of personal values and beliefs as a family-based aspect of sexuality education. Understood through a socially inclusive lens, caregivers, schools, and community partners taking on the educator role can act as social/societal supports in the provision of meaningful sexuality education, which would result in better long-term social outcomes (e.g., Renty & Roeyers, 2006). These external supports can compensate for social and communicative impairments (e.g., Finding 7, IB1-IB4) experienced by youth with high-functioning autism, and may otherwise prevent them from benefiting from informal forms of sexuality education (e.g., through the hidden curriculum). Because of their impairments, individuals with high-functioning autism may not be appropriate self-educators. However, increased self-awareness through targeted training may support the development of self-advocacy skills that could allow these individuals to better seek out appropriate sources of sexuality education.

From a socially inclusive perspective it would seem that peers are not appropriate educators, as they may not have the information (Finding 2, C1-C6) or skills (Finding 1, EA1-EA4) required to provide adequate education. However, peers can potentially act as either a support or a barrier. On the one hand, peers can exclude youth with autism through

misinformation, bullying, or in other ways (Finding 8, SB2). In contrast, proficient and accepting peers could help shape skills in acquisition, as well as reinforce and support the generalization of skills acquired through more formal and explicit education (Finding 6, SS3).

**Educator attributes.** Perhaps as important as who should be responsible for sexuality education was the notion of educator attributes. Aligned with youths' perspectives, most textual sources supported the notion that sexuality educators should have relevant education and experience, and should be comfortable with the subject matter. This was found across the literature, policy documents, and curricula. According to SIECUS, sexuality educators need specialized training that extends beyond a physical education background. In its view,

Sexuality education should be taught by specially trained teachers. Professionals responsible for sexuality education must receive training in human sexuality, including the philosophy and methodology of sexuality education. While ideally teachers should attend academic courses or programs in schools of higher education, in-service courses, continuing education classes, and intensive seminars can also help prepare sexuality educators. (2004, p. 21)

Similarly, Travers and Tincani (2010) and PHAC (2008) supported sexuality educators who are at ease with the topic and confident in their ability to teach it. Davies and Dubie (2012) recognized that educators may be uncomfortable or embarrassed when broaching private topics, but that this discomfort should not prevent them from providing the curriculum. Rather, they recommended that educators acknowledge their discomfort and use appropriate humour to alleviate it.

In line with caregivers, there was widespread support for the educator attribute of being well informed about autism. From the perspective of curriculum developers specifically in the field of autism, Davies and Dubie (2012) supported the provision of sexuality education by qualified persons who are knowledgeable about autism profiles and sexual content. In their view,

The most effective instructor for this [sexuality education] curriculum is someone who is familiar with strategies that maximize the learning of students with ASD. In addition,

completion of some form of professional development involving sexual health topics is recommended. Several educational backgrounds could form the foundation of the expertise needed to teach this curriculum. For example, instructors could be special or general education teachers, occupational therapists, speech-language therapists, health teachers, nurses, social workers, private therapists, parents, psychologists, or consultants. (2012, p. 5)

Likewise, Nichols et al. (2009) supported the view that educators should have experience in the use of sexuality assessments and developing sexuality learning plans for youth with autism.

Although knowledge of autism was considered important in related literature and curricula, this outcome was not found in policy documents. This is not surprising, as none of the policy documents examined as part of this study pertained specifically to sexuality education for individuals with autism.

One interesting discovery was that of opposing views toward alignment of goals with either the individual or others (usually the family). This result is linked to two levels of sexuality education. It is linked to educator attributes, in that it is the educator who supports the development and implementation of educational goals. It is also linked at a systems level to sexuality education in that formal education provided in organized settings (e.g., schools or community agencies) is influenced by administrative policy about youth involvement in decision-making processes. However, for the current finding, individual and family goal alignment is discussed from the educator-attribute perspective.

Some sources clearly supported the view that sexuality education goals should be aligned with families' opinions and values (e.g., Ballan, 2012; Chan & John, 2012; Hatton & Tector, 2010; MEDU, 2010a, 2010b; Tissot, 2009; Wolfe et al., 2009), whereas others supported individuals' right to choose goals for themselves (e.g., Hingsburger & Tough, 2002; Meister, Norlock, Honeyman, & Pierce, 1994; Murphy & Roy Elias, 2006). Some sources provided

nuanced views of individual and family goal development, recognizing that disagreement could arise between youth and family. As Sullivan and Caterino explained,

Service providers may find that there is a conflict between what they perceive as the needs of the child and the values and beliefs of their family. Such conflict may require in-depth communication between parents, educators and the affected individuals. (2008, p. 389)

Here, the authors acknowledged the possibility of disagreement about sexuality education content among stakeholders, and supported communication to resolve such discrepant views. Similarly, SIECUS advocated for sexuality education that allows youth to develop their own values, in light of those of their family and greater community:

Sexuality education seeks to provide an opportunity for young people to question, explore, and assess their own and their community's attitudes about society, gender, and sexuality. This can help young people understand their family's values, develop their own values, improve critical-thinking skills, increase self-esteem and self-efficacy, and develop insights concerning relationships with family members, individuals of all genders, sexual partners, and society at large. Sexuality education can help young people understand their obligations and responsibilities to their families and society. (2004, p. 19)

Such a view is echoed by various policy sources (e.g., McKay & Bissell, 2010; PHAC, 2008), and is exemplified by PHAC's statement that "sexual health education achieves maximum impact when it is planned carefully in collaboration with intended audiences" (2008, p. 18). Other sources specifically advocated for the primacy of voices of individuals in decisions relating to sexuality education goals (e.g., Hingsburger & Tough, 2002). Opinions regarding content among youth and their caregivers who were interviewed for this study were generally similar. Differences occurred more with regard to which topics should be emphasized. For example, caregivers placed more emphasis on safety than did youth. Caregivers and youth also differed on their views toward the ways sexuality education should be presented. For example, caregivers were more supportive than youth of sexuality education being provided separately for

boys and for girls. Thus, the literature was split regarding the alignment of goals, with some supporting a family approach and others advocating for putting the individual first.

When mapped onto the theoretical framework, knowledge and understanding of autism profiles, combined with technical and practical skills, can act as support for the provision of sexuality education by allowing educators to effectively teach a sensitive subject to individuals who may not have a social “filter” (Finding 7, IB5). Further, knowledge and skill can be understood as aspects of the trusted adults identified as external supports by youth and caregivers (Finding 6, SS1). Lack of these attributes can be linked to the external barriers of lack of adequate resources and limited information (Finding 8, SB1; SB4).

Regarding goal alignment, views can be understood in two ways. First, as mentioned previously, prior research has demonstrated that individuals with high-functioning autism may struggle to identify their needs. This may also be the case for sexuality education (Mehzabin & Stokes, 2011). Viewed another way, youth with high-functioning autism are able to self-identify and articulate their preferences. These views are not mutually exclusive. As a result, when seen through a socially inclusive lens, recognition of youth preference (in delivery and content) makes sense, as does the inclusion of (external) goals that may be difficult for youth to identify on their own. Insofar as the goals and methods of delivery increase the willing inclusion of the individual, they may be considered appropriate. For example, if partly separate gender groups result in better sociosexual skill acquisition, then such an approach may be appropriate. In these instances, evidence would guide the decision-making process.

**Provision.** Concerning provision of sexuality education, most of the literature and some curricula and resources supported individualized goals in a group setting, or individualized services. For example, PHAC stated that “the specific needs of individuals with disabilities vary

greatly from one individual to another and this should be taken into account when developing programs or curricula” (2008, pp. 9–10). This view was shared by the MEDU (2010a, 2010b), which sees sexuality education as needing to adapt to individual needs and accordingly advocated for what it calls “flexible groupings.” Analogously, Chan and John argued that nurse practitioners need to provide individualized sexuality education for youth with autism, stating: “when the time comes to approach topics of sexuality and sexual health, it is important to individualize each person’s experience and approach each patient by assessing his or her preferences, strengths, and needs.” (2012, p. 313). The view that goals should be individualized was well supported across all sources, including caregivers and youth. Individual provision, although supported by most caregivers and the literature, was less supported in curriculum-related documents and youth. According to the population-specific curricula developed by Davies and Dubie (2012) and Hénault (2006), group delivery was preferred over individual provision, however, individual delivery was deemed possible if a group setting was not feasible. Echoing the MEDU’s philosophy of flexible groupings, Davies and Dubie (2012) stated,

It is possible to use the curriculum to teach one individual; for such instances, we have provided suggestions at the end of each lesson on ways to adapt the teaching concepts. . . . There are no hard and fast rules about class size, since it largely depends on the strengths and challenges of individual students. However, we recommend a class of no more than 15 students (ideally fewer) with opportunities for students to work in smaller groups of 2 or 3 for some of the group activities. (p. 6)

Also related to provision was the facet of gender groupings. Whereas youth generally perceived no preference, and many stated no discomfort for mixed groups, most caregivers expressed a preference for some or all gender-segregated content provision. Most literature did not broach the topic of gender groupings. However, one study by Roth (2009) did posit that sexuality education should be provided to boys and girls separately. According to Roth, “many of the issues faced by males and females are different (e.g., hygiene, dating and safety skills).

Group members may also be more comfortable sharing experiences and issues with others of their own gender” (pp. 12–13). Likewise, Nichols et al. (2009) identified gender differences that require adapted curricula. They argued that “it is important to keep in mind that girls with ASDs generally learn about sexuality differently from either their neurotypical peers or boys with ASDs” (p. 223). Moreover, they argued for individualized provision in girl groupings as well. Hénault held a different view, stating: “whenever possible, it is always preferable to include both genders in a group. Boys are always curious to hear what girls think and vice versa.” (2006, p. 103). Some held a more middle-of-the-road view, citing the benefits of mixed and segregated genders, depending on the needs of the group and the context. Such a view is illustrated in the following excerpts:

Our curriculum is designed to be taught to a group consisting of both male and female students to allow for discussion and exchange of ideas. However, as the instructor, you know your students best and may choose to divide up the students. (Davies & Dubie, 2012, p. 6)

Although all the curriculum expectations can be achieved in either coeducational or same sex classes, addressing parts of the curriculum in same-sex settings may allow students to learn and ask questions with greater comfort. Same-sex settings may be of benefit to students ( . . . ) for the discussion of some health topics. . . . Such considerations are particularly relevant in the case of adolescent learners. It is also important to have time for coeducational learning, which can encourage learning about others, and about differences and commonalities among people, and allows for the development of relationship skills. Teachers should base their decisions about teaching in coeducational or same-sex settings on students’ needs. Different strategies may be required at different times, so that students have opportunities to learn in a variety of different groupings. (MEDU, 2010a, 2010b, p. 45)

In addition to divisions according to gender, provision of sexuality education in a partly or fully congregated setting according to diagnosis was also supported by most caregivers. This was not supported at a policy level; however some organizations that approach education from a socially inclusive perspective supported congregated education, when such an education is personalized to meet the individual needs of the student (e.g., Autism Ontario, 2007). Prior

research (e.g., Hatton & Tector, 2010; Hénault et al., 2003; Nichols & Blakely-Smith, 2009; Roth, 2009) and curricula (e.g., Davies & Dubie, 2012; Hénault, 2006) support the separate provision of sexuality education for individuals with high-functioning autism. Thus, provision of an adapted curriculum in a distinct setting is well supported in the literature.

On the topic of provision, the general theme that emerged from textual sources seemed to be that of individualized goals provided in a group setting, as much as possible. Views were split about gender groupings as they were between youth and caregivers to some extent. Arguments both for and against gender segregation were put forth in the literature, curricula, and in policy. Last, literature and curricula supported the provision of sexuality education in a separate setting, though policy neither supported nor refuted this premise. Understood through a socially inclusive theoretical framework, many of the same arguments put forth regarding goal alignment apply here. For example, the provision of sexuality education individually or in a group setting can be decided according to its outcome. As sexuality is, to a large degree, a social endeavour, minimally partial provision in a group setting would be necessary to teach and assess relevant social skills (e.g., Finding 2, C2). A similar argument can be made for gender groupings. At the same time, certain specific and private needs may warrant individualized teaching.

In relation to separate provision according to diagnosis, there is significant evidence that this type of delivery of formalized sexuality education is needed (Gilmour et al., 2012; Hellemans et al., 2007; Konstantareas & Lunskey, 1997; Mehzabin & Stokes, 2011; Ousley & Mesibov, 1991; Ruble & Dalrymple, 1993). As the current outcomes for individuals with high-functioning autism appear fair at best (e.g., Barnhill, 2007; Howlin, 2000), provision of a separate curriculum adapted to the particularities of the population is aligned with a socially inclusive theoretical lens. Regardless of the ways sexuality education is provided, because the

needs among individuals with high-functioning autism can be heterogeneous (Stokes & Kaur, 2005), the relevance and effectiveness of curricular goals will be predicated on their individualization (e.g., Nichols & Blakeley-Smith, 2009; Roth, 2009).

**Content.** The second dimension of sexuality education explored as part of the first research question was its content. This facet was reprised for Research Question 2, using textual evidence to support or qualify findings obtained as part of the previous question. To assist in the visualization of the results and supporting evidence, Table V1 illustrates the various content areas of sexuality education proposed by youth and caregivers, informed by recent relevant literature, policy, and curricula/resources (see Appendix V).

**Facts and safety.** From a policy perspective, SIECUS' guidelines for comprehensive sexuality education are perhaps the most often cited source for sound sexual educational policy. Their guidelines rest on six key concepts of sexuality: human development, relationships, personal skills, sexual behaviour, sexual health, and society and culture (2004, p. 15). The concepts and their related topics can be found in Appendix Z. Policies in the area of sexuality education, including that of SIECUS, identified fact-based information and safety as central to any sexuality curriculum, regardless of ability. SIECUS described one of the goals of sexuality education to provide safety-enhancing information:

Sexuality education seeks to provide accurate information about human sexuality, including growth and development, human reproduction, anatomy, physiology, masturbation, family life, pregnancy, childbirth, parenthood, sexual response, sexual orientation, gender identity, contraception, abortion, sexual abuse, HIV/AIDS, and other sexually transmitted diseases. (2004, p. 19)

In a review of sexuality curricula for students with disabilities, Wolfe and Blanchett (2003) identified facts and safety as key components, particularly as they related to biology and reproduction, health and hygiene, and self-protection and self-advocacy (Blanchett & Wolfe, 2002; Tarnai & Wolfe, 2008; Wolfe et al., 2009). Along the same lines as the policy and

literature, curriculum-developers also supported the provision of facts and linked them to safety (e.g., Davies & Dubie, 2012; Hénault, 2006; Nichols et al., 2009). Nichols et al., for example, identified the concepts of the body and abuse prevention as key components of their proposed sexuality education. Similarly, Hénault identified themes of physiological aspects of sexuality, STDs, HIV, and prevention, as well as sexual abuse and violence as part of a curriculum. Davies and Dubie (2012) discussed sexual anatomy, reproductive health, contraception, and STIs, as well as sexual intimidation, harassment, aggression, and abuse. Thus, in line with views of youth and caregivers, textual sources unanimously supported the inclusion of facts; also in line with caregiver and some youth perceptions, safety-based information in a sexuality curriculum was supported in the literature.

Mapping facts and safety as content items onto a socially inclusive framework, these topics are necessary components of a sexuality curriculum. Facts, including facts about safety, comprise the foundation of any sexuality curriculum, as evidenced by the literature on the subject. However, understood through social inclusion, facts about sexuality and safe sexuality will not result in different social outcomes on their own, since they are not linked to any acquisition of skill. More traditional formalized sexuality curricula focus primarily on knowledge. It would appear from research on social outcomes that current, more traditional approaches to sexuality education may be insufficient to assist individuals with high-functioning autism to be successful in adulthood (e.g., Goode et al., 1999; Howlin et al., 2000; Mawhood et al., 2000; Szatmari et al., 1989; Tantam, 1991). Thus, although a necessary component of sexuality education, facts and safety information require additional components to be considered meaningful from a socially inclusive perspective.

**Behaviours.** Beyond facts and safety, a second well-supported topic to be taught as part of a sexuality curriculum was that of contextualized sociosexual norms. Of importance from a policy perspective was the need for curricula that teach appropriate behaviours in a social context. This view was articulated by SIECCAN: “effective sexual health education programs . . . include program activities that address the individual’s environment and social context including peer and partner pressures related to adolescent sexuality” (McKay & Bissell, 2010, p. 11). SIECUS identified normalized behaviour as a key aspect of sexuality education, stating that “healthy sexuality requires the development and use of specific personal and interpersonal skills” (2004, p. 15). Ballan (2012), in research with caregivers, also supported the provision of sexuality education that taught social norms. To Ballan, caregivers should be trained to provide sexuality education to their children at home: “Family-based programs that target children with ASD with appropriate knowledge and skills for navigating normative sexual behavior associated with maturation and transition to adulthood are feasible and sorely needed” (p. 683). Teaching sociosexual normative behaviour also figured prominently in curricula and other practical resources, with many of these curricula teaching explicit rules of what to do and what not to do. For example, Davies and Dubie (2012) provided prescriptive behaviours to exhibit (or not) when flirting, specific topics to discuss when on a date, specific actions to take when ending a date, and so forth. Many sources also discussed teaching individuals how to distinguish between public and private behaviours (e.g., Davies & Dubie, 2012; Hénault, 2006; Koegel & LaZebnik, 2009; MEDU, 2010a; 2010b; Nichols et al., 2009). Overall, then, the teaching of sociosexual norms was well supported in the literature.

Understood through the theoretical lens, sociosexual behaviours and norms are perhaps the most important aspect of a sexuality curriculum for individuals with high-functioning autism,

as they represent actual changes in behaviour through positive skill acquisition and decreases in less appropriate behaviours. As a result of learning new sociosexually appropriate behaviours, individuals are better able to make and maintain social (e.g., Finding 8, SB2) and intimate relationships. Appropriate sociosexual behaviours may impact other areas as well (e.g., employment or living arrangements). Despite the importance of sociosexual behaviours in a sexuality curriculum, when mapped onto the theoretical framework it becomes clear that behaviours cannot be taught in a vacuum. In other words, sociosexual behaviours and norms require context to be significant. Harkening back to the previous finding, information (facts and safety) provide the foundation on which the behaviours are built. Taken together, information and behaviours become contextualized and result in sexuality education that can impact the social outcomes of individuals with high-functioning autism. On their own, these content areas are incomplete at best and barriers at worst (see Finding 8, SB3, for example).

**Pleasure and normalization.** Pleasure, a less common theme, was conceived to mean the teaching of the positive, joyful experiences that can come from sexuality and relationships with oneself and others. From an ethical perspective, Hingsburger and Tough (2002) bring forth the argument that individuals with disabilities should have their sexuality acknowledged and their sexual rights recognized, including the right to sexual fulfillment. They posited “that people are sexual beings should not be controversial; sexuality is part of who we are, how we experience the world, and its expression can be a source of personal pleasure” (p. 10). SIECUS (2004) upheld a pleasure-positive discourse to sexuality, stating for example that “people often kiss, hug, touch, and engage in other sexual behaviors with one another to show caring and to feel good” (p. 52), as well as “both men and women can give and receive sexual pleasure” (2004, p. 53) as part of their developmental messages. PHAC (2008) also recognized the role of

pleasure in people's lives, stating that individuals have a right to "pursue a satisfying, safe and pleasurable sexual life" (p. 6). The Davies and Dubie (2012) curriculum acknowledged the pleasure that can come from relationships with oneself and others. It explicitly taught the concept of physical intimacy with a partner that emphasized reciprocity of enjoyment (pp. 130–131). Hénault (2006) provided a similar component called "sensate focus." This tool aimed to teach individuals to have a novel sensory experience such that individuals could "explore the sensations associated with pleasure and share them with [their] partner" (p. 100). From a policy and a curriculum perspective, the Ontario revised curriculum (MEDU, 2010a) acknowledged pleasure, whereas the interim curriculum did not (MEDU, 2010b). The revised curriculum addressed pleasure on a few occasions, including in Grade 8 where it states that students will "develop their understanding about sexual health (e.g., about issues such as abstinence; the choice to delay first intercourse; setting sexual limits; safer sex and *pleasure*; use of contraception, including condoms, for pregnancy and STI prevention" (MEDU, 2010a, p. 204, emphasis added). Again, this curriculum is not currently being used in schools in Ontario. Thus, although to a lesser degree than other topics, enjoyment was addressed and supported in some of the literature and policies, as well as most of the curricula. This reflects the limited extent that this finding was also present with youth and caregivers.

As considered earlier, teaching appropriate behaviours or sociosexual norms was deemed an important aspect of sexuality education in the literature. Also important in the literature was teaching that sexuality itself was normal. From a policy perspective, SIECUS strongly advocated for normalizing sexuality for all human beings and across all abilities. On this subject, SIECUS succinctly stated that "sexuality is a natural and healthy part of living; all persons are sexual" (2004, p. 20) and included the normalization of sexuality as one of its key learning concepts. It

also stated its position on individuals with disabilities, affirming that these individuals “have a right to sexuality education, sexual health care, and opportunities for socializing and for sexual expression” (SIECUS, 2001, p. 2). PHAC (2008) correspondingly views sexuality as a central facet of being human, citing the World Health Organization working group’s unofficial statement on human sexuality (2002). The literature, to a lesser degree, also supported the normalization of the sexuality of individuals with disabilities (e.g., Hingsburger & Tough, 2002; Murphy & Roy Elias, 2006), including those with autism (e.g., Meister et al., 1994; Travers & Tincani, 2010). Ballan (2012), for example, discussed the need to acknowledge the sexuality of youth with autism and provide proactive education that would allow them to experience sexual fulfillment, explaining that “too often, the discussion when it does occur with providers, is restricted to problematic sexual behaviors exhibited by a child. Such discussions are reactive versus proactive and fail to contextualize the normative developmental sexual needs of children with ASD” (p. 683). Nichols et al. (2009) also recognized the need to normalize the sexuality of individuals with autism from caregivers’ perspectives. By creating a sexuality education plan for their child, caregivers are “acknowledging that [their] daughter is a sexual person and that this is a healthy and natural part of her growing up” (Nichols et al., 2009, p. 222).

Interestingly, normalization was absent in the Ontario (MEDU, 2010b) interim health curriculum, though it was included in its complete version (MEDU, 2010a). For example, as part of the Grade 6 updated curriculum, students are expected to learn about human development and sexual health. Sexuality is normalized through the “teacher prompt” exemplar below:

Having erections, wet dreams, and vaginal lubrication are normal things that happen as a result of physical changes with puberty. Exploring your body by touching or masturbating is something that many people will do and find pleasurable. It is common and is not harmful and is one way of learning about your body. (MEDU, 2010a, p. 162)

As noted previously, however, this curriculum is not currently in application. Again, the curriculum currently in use does not contain normalization of sexuality (MEDU, 2010b).

In sum, pleasure was an important topic found across the literature, as was the notion that sexuality is a normal aspect of being human, regardless of diagnosis. Though enjoyment was a minor theme with youth and caregivers, it was implicitly linked to the normalization of youths' sexual identities, especially in association with long-term outcomes such as being in a committed relationship and having children. Important for youth and caregivers was the shared view that sociosexual outcomes should strive to be more similar to the rest of society than different. This same theme emerged from all extant textual sources. Pleasure and normalization fit well in a socially inclusive theoretical framework, as they acknowledge and work against barriers to doing (understood as the physical experience of pleasure) and barriers to being (recognition of sexuality as normal for all people). Such a view is rooted in a social-relational theorization of disability (Reindal, 2008; Thomas, 1999), which is a cornerstone of the socially inclusive theoretical framework employed here. Consequently, sexuality curricula that integrate discourse of pleasure and normalization help to rebuke judgment (Finding 8, SB5), as well as promote socially inclusive outcomes.

**Delayed provision.** Although not identified by youth, more than half of caregivers brought up the need to balance the provision of sexuality education with youth developmental and physical maturity. This view was well supported in the literature overall. From a practical point of view, Nichols et al. (2009) supported the provision of education individualized to the age and developmental needs of the child, as explained below:

In general, teaching topics should be selected based on your [child]'s chronological age (e.g., as she approaches puberty she will need to learn about her body changes), whereas teaching strategies should be selected based on her developmental age and her developmental strengths and weaknesses. That is, her chronological age assists in

determining what she needs to learn, while her developmental age contributes to decisions about how she will learn best, and at what conceptual level she will be able to understand material. (2009, p. 223)

Some caregivers, it was noted earlier, argued that their children were less mature than their peers and thus required sexuality education that was adapted to their current level of maturity. This view was supported by research conducted by Stokes and Kaur (2005) who found that “at 15 years of age, adolescents with HFA [high-functioning autism] display a level of sexualized behaviour similar to 10-year-old typical adolescents [*sic*]. Similar, but smaller lags were evident for privacy behaviours and sex education” (p. 279). From a policy perspective, balancing development and physical maturity is also supported by PHAC (2008) and SIECUS (2004), as demonstrated by this excerpt from PHAC’s sexual-health guidelines:

Effective sexual health education is age-appropriate and responsive to an individual’s age, race, ethnicity, gender identity, sexual orientation, socioeconomic background, physical/cognitive abilities and religious background and reflects different social situations and learning environments. (p. 19).

Similarly, SIECUS provided developmental messages containing key information youth require for each topic. SIECUS (2004) provided four separate age levels that reflect stages of development: ages 5–8, 9–12, 12–15, and 15–18 (p. 24), allowing for flexibility in these developmental age groups for key messages to be taught. Thus, the adaptation of sexuality curricula to meet the developmental needs of individuals with high-functioning autism is well-supported. However, some sources argued that this adaptation should not sacrifice timeliness of provision and argued for proactive provision of sexuality education. This interpretation was supported by research conducted by Mehzabin and Stokes (2011), which states that the sociosexual needs of individuals with high-functioning autism must be addressed early to mitigate long-term negative effects. They explained, “if socialisation is not addressed at a young

age, the behaviour of persons with HFA [high-functioning autism] will continue to remain different from neurotypicals” (p. 620).

Support for starting sexuality education early and discussing it often has many advocates in the practical world of autism as well (e.g., Gerhardt, 2006; Koegel & LaZebnik, 2009; Mitchell, 2010). Gerhardt, for example, argued that “waiting until something inappropriate happens is not an option. . . . Start when children are young. Don’t make the mistake of waiting until the individual expresses interest in sex for education to begin” (2006, p. 45). Along these same lines, Nichols et al. (2009) were strong advocates “for being prepared, and in the area of sexuality this means creating a proactive plan for sexual learning and development” (p. 222). Therefore, textual sources support the view that sexuality education content should be adapted to meet the developmental and physical realities of youth with high-functioning autism, but these adaptations must not sacrifice timeliness of provision.

Considered through a socially inclusive lens, the validity of content adapted to the needs of individuals with high-functioning autism is not contested; it has been thoroughly argued in the literature. Timing of delivery can be understood a few different ways. First, recognizing that physical maturity outpaces developmental maturity is an important consideration. Mapped onto the theoretical framework, delayed developmental maturity is a recognized impairment related to autism. To compensate for this personal barrier, curriculum content must be adapted appropriately. Considering the research on sociosexual outcomes of individuals with high-functioning autism (Mehzabin & Stokes, 2011), sexuality curricula must be targeted and commence early. A parallel case can be made between sexuality education for youth with high-functioning autism and IBI for young children with autism. IBI “is a comprehensive approach that is used to teach a broad range of skills. . . . [It] aims to increase the rate of a child’s learning,

to bring their skills closer to those of typically-developing children” (CHEO, 2013). In the same way, proactive and adapted sexuality education could aim at improving the sociosexual developmental trajectory of youth with high-functioning autism, thereby minimizing the gap between them and their neurotypical peers. Thus, understood through a socially inclusive lens, appropriate sexuality education needs to be adapted to meet the needs of its target audience; however, it must begin early to improve social outcomes.

**Overarching education.** Whether sexuality education should occur as part of a discrete, formalized course or whether it should take place in more informal settings on an ongoing basis was not explicitly addressed in the majority of the works on the subject. However, most of the literature discussed sexuality education from a discrete perspective. In this sense, discrete sexuality education was implicitly supported across the vast majority of textual sources. To assist in the visualization of the results and supporting evidence, Table W1 illustrates the manifestations of sexuality education, as defined by youth and caregivers, and as informed by recent relevant literature, policy, and curricula/resources (see Appendix W).

Regarding implicit support for discrete provision of sexuality education, Davies and Dubie (2012), Hatton and Tector (2010), Hénault (2006), Roth (2009), and others created curricula that are meant to be explicitly taught in a formal setting. Similarly, Nichols et al. (2009) argued for caregivers to create a care team and develop a formalized sexuality learning plan for their children. Others also supported formalized sexuality education (e.g., Koller, 2000; Tissot, 2009).

Notwithstanding, there were some indications that sexuality education transcended classroom boundaries in some of the sources. For policy, PHAC clearly viewed sexuality education as an ongoing and overarching endeavor that requires support from all stakeholders

and across all settings, articulated in the following statement: “Access to effective sexual health education requires ongoing support in both formal settings, such as schools, community groups, health and social service agencies and in informal settings where sexual health education is provided by parents, caregivers, peers and others” ( 2008, p. 18). In an applied setting, sexuality education was promoted through the use of what some called “teachable moments.” According to Mitchell, such moments are crucial in providing youth with autism a concrete way of learning practical skills that are not taught in more formalized settings:

“Teachable moments” are when your person asks a question or mentions something they have heard about sexuality. These moments can also occur when watching a TV show, movie, song, book, newspaper, magazine, or anything else that interests or confuses them. Use these moments to share information or teach values and beliefs. (2010, p. 5)

These teaching opportunities echo what were considered critical incidents in caregiver interviews, emphasizing the importance of informal social and sexual education as situations arise between youth and their caregivers. Nichols et al. (2009) also described the relevance of teachable moments for youth with autism:

Always find opportunities for your daughter to practice her skills, and use lots of praise and reinforcement when she succeeds, or comes closer to succeeding. Life itself is full of teachable moments: they are there for you to utilize. During your day-to-day routine, when can you teach your child about boundaries, touch, and affection? How about at the grocery store, at restaurants, at the mall, at the movies, at school, while driving in the car, at family gatherings, or while watching television? Once you find yourself tuning into those perfect moments for teaching, you will be more and more likely to notice them and include them in your teaching for the day. This kind of learning is much more valuable than what she can learn from sitting in a formal social skills class. (p. 232)

The role of informal sexuality education was therefore seen as important in various textual sources. However, the bulk of the literature defined and discussed sexuality education as a formal and structured activity, and therefore the examples above augment the prevailing view that discrete forms of sexuality education are necessary for individuals with high-functioning autism.

When evaluated through a socially inclusive lens, formal and informal sexuality education can be deemed appropriate and complementary. The need for adapted (formal) sexuality education for youth with high-functioning autism is well-established; however, the need for more informal avenues of sexuality education is not. This is in part because of the impairments associated with autism, which can limit accessing more informal curricula. However, these informal curricula have historically been more subtle or implicit. More explicit impromptu lessons, those exemplified through the critical incidents in Finding 3, can be markedly beneficial in teaching behavioural skills and norms that would not occur in other settings (e.g., private behaviours; social faux pas). These occasions can also help further shape, reinforce, or generalize skills acquired in more formal or contrived settings. However, for these ad hoc lessons to be useful, educators require the attributes identified in Finding 2 (EA1–EA4). Said differently, formal and informal sexuality education can have a synergistic effect on the learning of individuals with high-functioning autism.

**Summary of findings related to Research Question 2.** The second research question looked at the ways extant texts informed the conceptualizations of sexuality education held by youth with high-functioning autism and their caregivers. The various textual sources (literature, policy, and curricula) generally supported the definitions of sexuality education put forth by youth and caregivers, as seen in the first three findings. Sexuality education was viewed as a multistakeholder endeavor, with caregivers viewed as the primary providers. In particular, value-based information was seen as a family responsibility, whereas other aspects of sexuality education were supported through various channels, including schools, community organizations, and medical and other professionals. Educator attributes were also deemed important in the literature, reflecting caregiver and youth views. In particular, specialized

training and comfort with the subject matter were seen as key educator attributes. Knowledge of autism was also seen as important, though this finding was not reflected in policy documents, possibly because such documents were not autism-specific. Alignment of sexuality education goals, described as both an educator attribute and a systemic attribute, was divided. Although some sources supported alignment of goals with youth views, other sources supported alignment with caregiver views. Some sources provided a more nuanced view, supporting goals that valued views of individual members in a family.

For sexuality education provision, the majority of sources supported individualized goals in a group setting. To a lesser extent, individualized provision was supported as well. Also, although gender was not widely discussed in the literature, there was no consensus among the sources that did do so. This division reflected the split views found across youth and caregivers. Regarding content, fact-based information combined with discussions about safety were esteemed across all textual sources. In addition to these topics, support for the teaching of sociosexual norms was also well documented across the literature, policy documents, and curriculum sources. The topics of normalization, and to a lesser extent pleasure, were discussed in some texts. Mirroring caregivers' views, there was strong textual support for the provision of sexuality education that is adapted to an individual's physical and developmental maturity. However, many sources also argued that adapted sexuality education must still be provided proactively.

**Answering Research Question 2.** Thus, to answer Research Question 2, youth and caregivers' conceptualizations of sexuality education as a curriculum that encompasses behavioural norms, facts and safety, normalization of sexuality, and to a lesser degree, pleasure, were generally well-supported by the literature. Youth and caregivers both understood sexuality

education as the responsibility of caregivers and schools, with caregivers also identifying the role of community partners. Again, these views were strongly supported in the literature. Educators require trustworthiness, relevant knowledge, and experience related to sexuality education (youth) or youths' autism profiles (caregivers). Literature on the subject upheld the importance of relevant knowledge and skills, and familiarity with autism profiles, but did not generally support personal educator attributes such as trustworthiness. Youth and caregivers conceived of sexuality education as taking place as a mix of 1:1 and group-based delivery. Overall, literature backed the notion of individualized goals taught in a group setting. Youth also understood sexuality education as taking place in mixed-gender groupings, whereas caregivers saw it being delivered partly or fully segregated according to gender. Document evidence was split on this subject. Caregivers understood sexuality education as being adapted to the developmental level of their child(ren). Textual sources supported developmentally appropriate, proactive delivery. Finally, caregivers also conceptualized sexuality education as a mix of formal and informal activities that took place across multiple settings over time, with some formal education taking place separately according to diagnosis. The literature upheld this view. A visual representation of the dimensions that emanated from these findings, mapped onto the conceptual framework, and linked to the research questions can be found in Appendix AA. Having presented the central discoveries of this study, I now turn to the synthesis portion of this research, where I discuss the meanings derived from these findings.

## CHAPTER 7: SYNTHESIS AND CONCLUSION

### Introduction

The purpose of this study was to develop conceptual framework of sexuality education, privileged by the voices of youth with high-functioning autism and their caregivers, and as informed by the literature. In addition, this study sought to identify the personal strengths, societal supports, and personal and societal barriers that facilitate or hinder access to sexuality education for these youth. It was hoped that this study would inform emerging theory through the development and application of a socially inclusive theoretical framework in the context of sexuality education and autism. It was also hoped that this research project could inform policy, program, and curriculum development in the fields of sexuality education and autism, which could potentially have positive implications for the social outcomes of individuals with autism. Most importantly, this study aimed to give voice to youth with high-functioning autism on the very personal and important topic of their sexuality education.

For this qualitative study, 20 individuals from eight families were interviewed, including nine youth and 11 caregivers. Data obtained from six youth and eight caregiver surveys, as well as an extant text analysis were used to support or qualify the findings obtained through the interviews. The following research questions were developed to address the goals of this study:

1. What does sexuality education mean for youth with high-functioning autism and their caregivers?
2. How do prior literature, policy, and curricula in this field inform this definition?
3. In the context of sexuality education for youth with high-functioning autism, what are the supports and barriers encountered by these youth and what are their impacts?

In the previous chapters, eight major findings were uncovered from this study that answered the above research questions. The data presented in the preceding chapters, organized

by individual finding, were used to answer the research questions. In this chapter, I attempt to come to a deeper understanding of the findings. In other words, whereas previous chapters deconstructed the information garnered from various sources and exposed them as individual findings, this chapter reassembles those pieces of information to create a meaningful and holistic picture. To accomplish this, I engaged in a variety of data-processing steps. As a first step, data were organized according to the research questions. Next, thematic categories were created that matched the concepts found in my theoretical framework. As I reviewed the various textual sources, analyzed the survey results, and coded and recoded the interview transcripts and related data, thematic categories were further expanded and refined. I actively sought discrepant views and negative cases and attempted to reconcile these views by acknowledging them or refining my thematic categories accordingly. Comparisons were made between various demographic factors across youth (age, language, and school board) and caregivers (language, child(ren)'s school board, and gender). No relationships were found that impacted the findings. Throughout this analytic process, the socially inclusive theoretical framework developed for this study was revisited and further honed. As a result of these analyses, eight findings are summarized below.

### **Summary of Findings**

Eight major findings were discovered in this research project and were presented in the two previous chapters. These findings were presented according to the three research questions that guided this study. The first four findings sought to conceptualize sexuality education from youth, caregiver, and extant-text perspectives. Sexuality education was defined according to its form and content. Specifically, the first finding considered the modalities of sexuality education, whereas the second finding examined its content. The third finding touched on both form and content. The fourth finding revisited and provided evidence for or against the definitions

provided in the first three findings, integrating relevant literature, policy documents, and curricula.

Regarding form, youth and caregivers agreed on presentation, responsibility, and the quality of educator, whereas they disagreed on the priority of responsibility, educator qualities, and gender grouping. An overwhelming majority of youth and caregivers thought caregivers and schools should be primary providers of sexuality education. This view was well supported in the literature. Most caregivers identified community partners as also responsible for providing sexuality education, whereas only one youth did. This finding was also well supported in the literature, with various professionals and community partners cited as potential educators. With very few exceptions, peers and youth themselves were generally not perceived as being good educators across all informants.

Both youth and caregivers cited that educator qualities impacted the quality of sexuality education. Whereas youth stressed the importance of educators' personal traits and relevant knowledge/experience, caregivers placed more emphasis on educators' knowledge of autism, trustworthiness, and alignment with family goals. Textual sources supported the importance of relevant training and ease with subject matter in determining the effectiveness of sexuality educators. Theoretical and applied literature also supported the importance of knowing about learners' profiles when teaching about sexuality, though this result was only found in texts specific to autism. Results pertaining to alignment of goals were divided. Some sources supported aligning goals with youth views, whereas others supported alignment with caregiver goals. A third view favoured seeking an outcome that acknowledged all family members' views.

Regarding provision, all youth and a vast majority of caregivers believed that sexuality education should be provided as 1:1 and/or group-based delivery. The literature generally upheld

individual goals as part of group-based delivery of sexuality education, though some sources also acknowledged that individual provision may sometimes be appropriate. On the issue of gender groupings, the majority of youth did not have a preference between mixed or segregated gender groupings, whereas an overwhelming majority of caregivers believed that sexuality education should be provided either partly or fully segregated by gender. Texts on this subject were divided, with some texts favouring mixed-gender groupings and others promoting separate groupings. Caregivers also felt that formal sexuality education should be provided at least partly separately according to diagnosis. This finding was supported by the literature as well.

Another dimension of sexuality education that was explored as part of this study was that of content. More precisely, this analysis looked at what should and should not be included as part of a sexuality education curriculum. A vast majority of youth wanted to learn specific sociosexual behavioural rules or timelines. Similarly, though more broadly stated, all caregivers affirmed that contextualization of information through explicit teaching of social/sexual behaviours and conventions should be a central component of a sexuality curriculum. This result was very well corroborated by the literature. A related finding was that an overwhelming majority of parents wanted to normalize their child(ren)'s sexuality through sexuality education. This finding was also supported in the literature. Pleasure was a less common theme explicitly discussed by two youth and two caregivers, though the theme was embedded in some discussions of normalized sexuality of individuals with autism. This theme, though also much less common than other content areas, was identified in some textual sources, particularly in population-specific curricula. Youth and caregivers related the importance of facts in a sexuality curriculum. Caregivers associated teaching about facts with safety, as did some youth. Facts and safety were

also viewed as important in both practical and theoretical literature, and were also generally closely linked to one another.

Regarding timing of provision, a majority of caregivers believed that sexuality education should be provided according to the physical and developmental maturity of the child. As such, sexuality curricula may need to be adapted to meet the needs of various individuals. The majority of texts supported this outlook; however, emphasis was also placed on the provision of timely sexuality education. Thus, the literature supported the argument that sexuality education should be adapted to meet the educational situation of the individual, but that content must still be provided proactively to support the individual's healthy sexual development.

A finding that emerged from all caregivers but not from youth was that sexuality education should transcend discrete classroom boundaries. Caregivers described critical incidents where new behaviours or situations occurred that related to their child's sexual/social development, indicating a need for prompt, informal sociosexuality education for their child(ren). Many caregivers acknowledged feeling uncomfortable or ill-prepared to respond to these incidents. Nonetheless, the vast majority of caregivers who shared critical incidents used them as teachable moments to discuss sexuality with their child(ren). Although the bulk of the literature treated sexuality education as a discrete and formalized activity and therefore implicitly supported this view, the perception that sexuality education comprised both formal and informal aspects was nonetheless supported by a minority of sources.

The first four findings centred on defining sexuality education from various perspectives. The last four findings focused on identifying the supports and barriers to accessing this sexuality education. Findings 5 and 6 explored internal strengths and external supports, whereas Findings 7 and 8 reviewed personal and social/societal barriers. Although an overwhelming majority of

youth displayed personal strengths (during interviews or described by caregivers), many youth struggled to identify personal strengths related to sexuality education. All youth were, however, able to identify more concrete attributes. All caregivers were able to identify a number of personal strengths for their child(ren) related to sexuality education, including intelligence and affective empathy. Some of these attributes were seen as both strengths and challenges, depending on the context. For example, most caregivers identified openness/interest toward the subject as a personal attribute, whereas most of them also saw this attribute as a potential barrier. Likewise, some caregivers identified concrete thinking as a strength related to sexuality education, whereas an overwhelming majority of caregivers viewed this attribute as a potential barrier.

Regarding external supports, both youth and caregivers identified caregivers and other trusted adults as advocates in accessing sexuality education. Youth and caregivers differed regarding the Internet and other media. Youth identified the Internet and other media as potential resources, although this view was with reservations for many youth. Caregivers, in contrast, perceived the Internet and other media as potential barriers. A third of youth and just under half of caregivers identified peers as good resources when these peers were available.

The final two findings were concerned with personal and social/societal barriers to sexuality education for youth with high-functioning autism. As for supports, caregivers were generally better able to identify personal and social barriers for youth than youth themselves. All caregivers identified barriers for their child(ren), whereas a third of youth did not perceive any personal obstacles that would prevent them from accessing sexuality education. Caregivers identified various forms of literal thinking as a major barrier, whereas only one youth did. Associated with the previous finding on adapted curriculum provision, youths' delayed

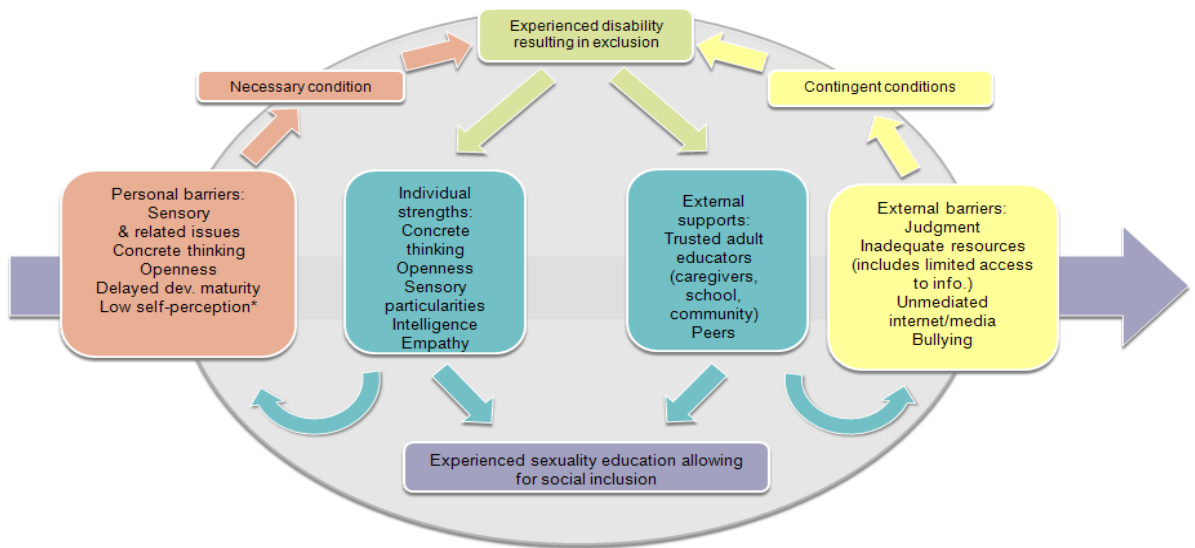
developmental maturity was viewed as a barrier by the vast majority of caregivers. Sensory issues, anxiety, or attention were identified as personal barriers by most caregivers, but only a third of youth. One personal barrier that was identified by a third of youth but not by their caregivers was that of negative self-image or low levels of confidence.

Concerning external barriers, many more social and societal barriers were named by caregivers than by youth. Almost half of youth and most caregivers identified lack of friends or bullying as an obstacle, with consequences that extended beyond the realm of sexuality education. Caregivers also identified unmediated access to media and technology (particularly the Internet) as a barrier to appropriate sexuality education. In contrast, youth identified limited access to information as a barrier. Caregivers also mentioned resource inadequacy and judgment by others as barriers to sexuality education. Taken together, I mapped the findings onto the socially inclusive theoretical framework iteration of sexuality education (see Figure 8).

## **Synthesis**

Following these analytic steps in which the essence of data were extracted, I attempted to reassemble the information according to broad themes that connected all findings and further answered the research questions at a deeper level. In all, the following five overarching themes emerged from the findings:

- Necessary and sufficient sexuality education
- Safety, pleasure, and normalization
- Situating sexuality educators
- Divergent perspectives of sexuality education delivery
- Stability and fluidity of supports and barriers



\*Not true personal barrier - Consequence of external barrier.

Figure 8. Tentative hybrid socially inclusive theoretical framework of sexuality education.

The eight findings obtained from the analyses are grouped to answer the three research questions. The first four themes are concerned with providing in-depth understanding of the findings obtained in Research Questions 1 and 2. The last finding offers insight into the most salient aspects of Research Question 3. Although these themes answer specific research questions, they also pool from and cut across all findings. To assist in the visualization of the final findings, Table BB1 organizes the data from various sources, categorized according to research question and finding. This table can be found in Appendix BB.

As this is a qualitative analysis of the data, the meanings ascribed to them are necessarily an imposition of my perception of this study's outcomes. Thus, it is a subjective endeavour. Other interpretations are certainly possible and plausible. Nonetheless, having immersed myself extensively in the data, I have attempted to provide a coherent, well-supported interpretation of

the findings. In the remainder of this chapter, I provide an in-depth discussion for each of the major themes as they relate to the eight previously presented findings, in light of the literature, as well as the theoretical framework. Following this discussion, a summary of the final findings is provided, and the theoretical framework proposed for this study is revisited and refined. Next, I provide some suggestions for future research endeavours, identify the limitations and contributions of this study, and conclude with some final thoughts.

### **Research Questions 1 & 2**

**Sexuality education: Content and implications.** Some key sexuality education content areas specific to youth with high-functioning autism were identified by various sources as part of this study. In line with the HMCD underpinning of this study, the resultant conceptual framework proposed is dispositional and evolutionary. Correspondingly, meanings were found through common language and usage, with an awareness of inevitable changes in these meanings over time (Rodgers, 1993). Thus, the conceptual framework proposed reflects current usage in this study's setting: It is time and context bound. The perceived content of sexuality education for youth with high-functioning autism garnered from youth, their caregivers, and the literature can be summed up and grouped according to the following categories: facts and sociosexual skills, safety, enjoyment, and the normalization of sexuality. The next section explores each of these categories in detail and concludes with a discussion of these themes in light of the theoretical framework.

**Necessary and sufficient sexuality education.** Across all caregivers, a majority of youth, and all sources of literature, fact-based information was seen as a central aspect of sexuality education (Finding 2, C1). Such a finding is unsurprising. From a youth perspective, it would seem that this was a well-liked topic because it was concrete and therefore well-aligned with their literal-thinking attribute (Finding 5, IS4). As a result, youth were generally successful

when learning about these aspects of sexuality in an educational setting. It is conceivable that youth liked learning about facts because they were a “safe” topic for them. Unlike learning about social and sexual norms, where correct answers are multiple, highly context-dependent, and often cannot be memorized, the correct answers to fact-related questions were finite and unchanging.

Although youth with high-functioning autism may enjoy learning fact-based information because such learning is met with relative success, one can argue that youth do not necessarily always comprehend the fact-based information they are accessing. Such an interpretation is consistent with the literature (Ballan, 2012; Griffin-Shelley, 2010; Hellemans et al., 2007; Konstantareas & Lunsky, 1997; Mehzabin & Stokes, 2011; Stokes & Kaur, 2005). This assertion takes the view that youth have a hard time translating theory into practice, a theme identified as part of the initial literature review. However, this assertion may need to be taken a step back, as it seems from the findings of this study that youth do not understand the theory to begin with. This harkens back to the theme of “invisible disability” that emerged as part of Finding 8 (SB5). Youth with high-functioning autism have average to above-average intellectual ability, a personal strength identified by all caregivers and one youth as part of Finding 5 (IS2). At the same time, these youth are very concrete and literal in their thinking, struggling with figurative and nonverbal language. This personal barrier was identified by the vast majority of caregivers and one youth as part of Finding 7 (IB3). As a result, youth may not understand or may misinterpret important aspects of the sexuality education provided to them. Due to their intellectual ability, memory, and verbal skills, their limited understanding of sexuality is often masked, and may not be caught by sexuality educators (e.g., Kalyva, 2010). Such limited understanding poses a tangible barrier to benefiting from sexuality education that is not adapted

to their concrete interpretations of language. To address this issue, it may be of use for sexuality education to investigate the extent to which youth understand the concepts they are learning. Self-reports and rote assessments of information are not reliable in demonstrating deep understanding for individuals with high-functioning autism (Mitchell & O’Keefe, 2008; Roth, 2009) Therefore, alternative and more valid means of assessing youth understanding of sexuality may be of benefit (Mehzabin & Stokes, 2011). One possible means of accomplishing this is through a curriculum that teaches both knowledge and its application.

Concrete thinking and intelligence combined can also have consequences for youths’ unmediated or uncontextualized use of media and technology. As demonstrated in the findings, the landscape of sexuality education has become increasingly complex, especially with new technologies. The proliferation of technology and media in personal lives (e.g., cell phones in high school settings, unmediated wireless Internet access, and social media) bring with them new opportunities and new challenges. Youth may benefit from the use of media and technology in learning about sexuality and in engaging socially with others. However, the nature of their impairments may put them at increased risk for victimization or inadvertent victimizing. Consequently, current relevant sexuality education may benefit from the inclusion of information and skills related to media and technology that are adapted to the learning particularities of youth with high-functioning autism. Ensuring healthy and equitable access to media and technology can enhance the overall social inclusion of these youth. Finally, sexuality education that includes content identifying and building supports to improve youths’ self-perceptions (including self-advocacy skills) can act as a powerful tool in promoting their social and sexual rights (Aylott, 2000; Hingsburger & Tough, 2002). Moreover, strength-based education has proven to be a promising intervention in reducing bullying victimization (e.g., Rawana, Norwood, & Whitley,

2011). These areas can positively impact youth safety and enjoyment, and increase the normalization of their sexuality overall.

Caregivers, for their part, also viewed fact-based information as an important but absent part of sexuality education. In addition to facts, caregivers, like youth, stressed the importance of learning about sociosexual norms (Finding 2, C2). Facts and sociosexual skills seemed inextricably linked to one another. I posit that facts may be a *necessary* aspect of sexuality education, whereas sociosexual norms may be a *sufficient* aspect. Facts may be necessary as they provide the foundation for healthy sexuality to occur. However, sexual facts on their own may not be sufficient for healthy sexuality to manifest itself. In addition to facts, youth require learning-appropriate and healthy sociosexual behaviours. Thus, sociosexual norms can be viewed as a *sufficient* aspect of sexuality education for youth with high-functioning autism.

The view that sexuality education is about teaching both knowledge and behaviours is upheld in the literature. In creating comprehensive sexuality education guidelines, for example, SIECUS (2004) addressed these precise aspects:

The task force sought to create an organizational framework of the important knowledge and skills related to sexuality and family living. To do this, the task force first determined the life behaviors of a sexually healthy adult which serve as outcome measures of successful sexuality education. They then compiled the information and determined the skills necessary to achieve these life behaviors and organized them into key concepts, topics, subconcepts, and age-appropriate developmental messages. (p. 15)

That effective sexuality education should be based on models that have been proven to change behaviour is well supported in research and policy (e.g., Albarracin, Gillette, Earl, Glasman, Duranti, & Ho, 2005; Kirby, Laris & Rolleri, 2007; McKay & Bissell, 2010; PHAC, 2008). For example, in a review of sexuality curricula for individuals with special needs conducted by Blanchett and Wolfe (2002), the inclusion of “cognitive” and “affective” behavioural goals were one of the stipulated criteria used in determining their appropriateness. Indeed, programs that

aim to increase knowledge, although important, may be insufficient on their own to meaningfully assist individuals in developing healthy sexualities, corroborated by this statement by PHAC:

Programs that are exclusively directed at increasing the knowledge of an individual are often successful in reaching this objective. Although useful in this regard, focusing only on providing factual information about sexual health may not be sufficient or effective in reducing negative sexual health outcomes. While an individual exposed to this type of educational programming may possess a high level of sexual health knowledge, it is unclear whether that knowledge will translate into behaviours that can enhance sexual health. (2008, p. 34)

As identified above, PHAC supported sexuality education for all individuals (not just individuals with autism) that combines knowledge with behaviour change. Sexuality education, then, seems to be about the application of knowledge in daily life. A conceptualization of sexuality education based on both knowledge and behaviour helps address the personal barrier of superficial understanding identified in Finding 7 and exposed in the literature review, because understanding of the concepts can be verified in their application. This is especially relevant in addressing inappropriate social and sexual behaviours such as obsessive and following behaviours, found in survey responses.

Sexuality curricula that adopt observable and measurable behavioural objectives are supported by an ABA approach, which is widely accepted as the most effective intervention for teaching individuals with autism (Gulick & Kitchen, 2007; Simpson, 2001; Wolfe et al., 2009) and is increasingly supported for teaching sexuality education (e.g., Ballan, 2012; Gerhardt, 2006; Wolfe et al., 2009). Moreover, support for both knowledge and behaviour-based sexuality education can be found at a local policy level as well (MEDU, 2010a; 2010b), and is aligned with Policy/Program Memorandum 140 (PPM 140) released by the MEDU in May 2007. Specifically, this policy requires the incorporation of instructional methods based on the principles of ABA into programs for students with autism in publicly funded school boards across Ontario (MEDU, 2007). In summary, sexuality education was found to be conceptualized

as being about facts and about sociosexual norms. Although facts were seen to provide the foundation for skills to be learned, skills were seen to be the ways in which knowledge is applied. Such a conceptualization was supported by youth, caregivers, and textual sources.

**Safety and pleasure: Normalizing the heart.** A second content category elicited by all caregivers, some youth, and across extant texts was that of safety (Finding 2, C3). The theme of safety was most often associated with fear, and was often echoed in the research as well (e.g., Nichols & Blakely-Smith, 2009; Ruble & Dalrymple, 1993). As the literature suggests, such fears are not unfounded, as individuals with disabilities are at an increased risk of victimization and abuse (e.g., Mansell et al., 1998; Sobsey, 1994). As part of this study, caregivers shared affecting examples of the precarious behaviours engaged in by their children that put them at risk (e.g., seeking a partner using an online dating service, touching peers inappropriately, and engaging in behaviour akin to stalking). Hingsburger and Tough (2002) articulated the importance of acknowledging caregivers' fears as follows:

It is important to note that parents (Pendler & Hingsburger, 1990), like staff have some reasonable fears regarding people with disabilities becoming sexual, such as the possibility of sexual exploitation, sexually transmitted diseases, unwanted pregnancy, and the ability to parent, that need to be addressed. Acknowledging that these possibilities are realistic and then coming to solutions for protection that involve the person with a disability being their own first line of defense is important (Hingsburger, 1995). (p. 11)

As illustrated above, the literature points to the importance of acknowledging and validating the dangers that exist for these youth in order to confront these realities in a positive manner, and to move the discussion beyond fear alone.

Often, the discourse of sexuality addresses the right to say *no* to unwanted sexual advances. Less common, however, is a person's right to say *yes*. A case in point for this can be found in Blanchett and Wolfe's (2002) review of sexuality curricula for students with disabilities. This comprehensive review uses a long list of criteria in assessing the

appropriateness of various curricula. Among these criteria were some positive dimensions related to sexuality such as “Relationships and social skills.” However, although there was the concept of “Saying ‘no’ to sex,” there was no evaluation of the concept of “Saying ‘yes’ to sex.” In addition, no criteria based on pleasure or enjoyment were found in assessing the curricula. Yet the dimension of pleasure in sexuality can be deemed highly important in a discourse of social inclusion, particularly as it relates to *shared* pleasure.

The theme of pleasure was a minor finding when compared to the other content areas enumerated by youth and caregivers, and found in the literature (Finding 2, C5). For many youth, it is plausible that they may not have been aware of enjoyment as a legitimate dimension of sexuality, and for this reason did not raise the topic. Most caregivers may have been reluctant to discuss this aspect of sexuality because of discomfort. This view is at least in part supported by prior research with caregivers of neurotypical youth. Such research has demonstrated that although topics related to pleasure are perceived to be important, few caregivers address them with their children, focusing instead on discussions about safety (Sieswerda & Blekkenhorst, 2003). Alternatively, caregivers in this study may have assumed that pleasure was implicitly understood to be a part of sexuality and may not have broached the topic for that reason.

Although some works of literature explicitly discussed shared sexual enjoyment as a goal (e.g., Hatton & Tector, 2010; Tarnai & Wolfe, 2008), much of the literature either did not mention pleasure or alluded to it via technical discussions of self-pleasuring (e.g., Koller, 2000). Masturbation is one dimension of sexual pleasure that plays an important role in many persons’ lives, and is deemed an important component of sexuality education by advocates, as it acknowledges and thus normalizes the sexual identities of these individuals. Yet, when taught on its own, masturbation may provide an incomplete picture of sexuality. In addition to self-

pleasure is the facet of mutual pleasure, as experienced in consensual relationships with others. Arguably, this dimension of sexuality is closely linked to the normalization of the sociosexual identities of individuals with high-functioning autism, which was another content area elicited by caregivers and the literature (Finding 2, C4). Again, Hingsburger and Tough (2002) offered insight into this oft overlooked aspect of sexuality education:

Relationship training is of utmost importance for [individuals with disabilities]. It is also more than social skills training. It is teaching about personal safety. It is teaching that the ‘culture of terror’ is over and that their sexuality is welcomed and celebrated. (. . .) For sexuality education advocates who focus on biology and reproduction, discovering that the heart was more controversial than the genitals was a surprise. Nevertheless, the heart must be emphasized, because for people with disabilities, existence of loving desires is a potent argument for the acceptance of the whole person. Awareness of our common relationship needs will allow others to see [persons] with disabilities as sexual and loving beings. (p. 12)

The theme that “sex matters,” which emerged in the literature review, bears revisiting here. In light of the above quotation and the findings of this study, it is conceivable to shift the emphasis slightly away from the sexual aspect of sexuality education and toward the relationship aspect. As Hingsburger explained in a professional-development module targeted for frontline staff working with individuals with disabilities, sex education may be a misnomer for what is needed:

In my own agency here, I don’t do sex education with people with disabilities here because I don’t even like the term, OK. Because firstly, when you say sex education to a parent or a (school) board, um, they don’t hear sex education, they hear SEX! education. I mean that’s what they hear, OK. And when you actually take a look at any good curriculum on “sex education” if you will, this much (holds up thumb and index finger to show small amount) of it is about intercourse, and this much (holds arms far apart in front of him) is about relationships, is about friendships, about reciprocity, about hygiene, about all these other sorts of things. So why are we calling it after the smallest part? (Open Future Learning, 2012)

Such a philosophy of sexuality education can be seen as one that promotes a more global and inclusive view of healthy sexuality. Support for the dimension of relationships in sexuality education is espoused by both SIECUS and PHAC. According to SIECUS (2004), sexuality

education requires explicit teaching about relationships, including the right to refuse as well as the right to consent to shared sexual experiences, as articulated below:

Sexuality education seeks to help young people develop interpersonal skills, including communication, decision-making, assertiveness, and peer refusal skills, as well as the ability to create reciprocal and satisfying relationships. Sexuality education programs should prepare students to understand sexuality effectively and creatively in adult roles. This includes helping young people develop the capacity for caring, supportive, non-coercive, and mutually pleasurable intimate and sexual relationships. (p. 19)

At a provincial level, the inclusion of pleasure in its revised curriculum also demonstrates a small step toward recognizing the positive facets of sexuality in addition to the discourse of fear (MEDU, 2010a). However, this curriculum remains unused, due to resistance from a vocal minority (CBC, 2010; Opeha, 2010).

From a youth perspective, being in a committed romantic relationship was seen as either a definite or a possible part of youths' adult vision of themselves. All of them explained that such a relationship was something they would want to pursue when they were older. Likewise, all caregivers also saw a future for their children that included the possibility of being in a committed romantic relationship. Caregiver survey results corroborated this finding. This finding is reflective of similar results in research conducted by Nichols and Blakeley-Smith (2009), but contrasts with findings in Ballan's (2012) research.<sup>10</sup> Caregivers exemplified their role as external supports in promoting their child's sexual education and development, as was observed in Finding 6 (SS1). Some expressed more uncertainty regarding whether such a relationship would materialize or how their child would cope with relationship woes, but still conveyed a sense of hope regarding the development of their child's social and sexual identities. Hence, conceptualizations from all sources of the content of sexuality education included the topic of

---

<sup>10</sup> Both studies involved caregivers of youth across the autism spectrum, however, youth in the Ballan (2012) study were younger (6–13 years, no mean reported) than youth in the Nichols and Blakeley-Smith (2009) study (8–18 years, mean age: 13 years). This partially explains the difference in the findings.

safety. To a lesser extent, though perhaps as importantly (if not more so), youth, caregivers, and some of the literature identified the content area of pleasure. In particular, the need for content that addresses and supports both personal and shared sexual relationships was identified as part of policy-related and theoretical literature. These content areas were linked to the normalization of the social and sexual identities of individuals with high-functioning autism, which were well-founded in caregivers' voices and across the literature (Finding 2, C4).

**Sexuality education content and the theoretical framework.** Behaviourally based sexuality education was missing, according to youth and caregivers. In this sense, it acted as a barrier in that there were inadequate/unresponsive resources (Finding 8, SB4). A conceptualization of sexuality education content that includes both fact-based information and sociosexual skills is congruent with a socially inclusive framework as it works to address the personal trait of literal understanding, identified as part of Finding 7 (IB3). In this manner, it helps overcome an attribute that acts as a barrier in this context. Also, this understanding of sexuality education is socially inclusive because a skill-based intervention works to change the behaviours of students. Consequently, it can make a positive difference in the social and sexual lives of these individuals, which is an improvement on their social inclusion. Evidence-based services, guided by their outcomes, are associated with familycentric practices in the literature (e.g., Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001; Holburn, Jacobson, Vietze, Schwartz, & Serson, 2000; Lyons, 2009a; 2009b; Ruble et al., 2012; Stroul, 1993), with familycentricity linked to social inclusiveness (Gougeon, 2011).

Safety and pleasure can be understood as two dimensions that comprise the construct of normalization of the sexualities of individuals with high-functioning autism. Although both were conceived as part of sexuality education, enjoyment had a much smaller presence across all

sources. Research on the discourse of pleasure in sexuality education corroborates its continued underrepresentation and its overassociation with danger (Lamb, Lustig, & Graling, 2013).

Caregivers advocated for the normalization of their child(ren)'s sexualities, and this was well supported in the literature (Finding 2, C4). From an educational perspective, researchers have demonstrated that caregivers often do take on various advocacy roles for their children with special-educational needs (e.g., Duquette, Fullarton, Orders, & Robertson-Grewal, 2011). In this study, caregivers and supporting literature acted as positive forces in changing judgment toward youths' sexuality encountered in society. Such attempts to normalize the sexuality spectrum exhibited by these youth falls in a socially inclusive framework of sexuality education.

One way caregivers advocated for normalization was through hopes that youth would enter into intimate relationships with others. Similarly, youth held such expectations for themselves. These openly articulated beliefs presupposed a valuing of enjoyment experienced through sexual relationships with others, on the one hand, as well as supported the notion of normalized sexuality for individuals with autism, on the other. The topic of shared enjoyment is concomitant with a socially inclusive perspective as it bridges a gap in the lives of individuals with high-functioning autism (e.g., Hellemans et al., 2007; Van Bourgondien et al., 1997).

Another way in which normalization of sexuality may be achieved is through education on safe enjoyment of media and technology. Similarly, education that seeks to improve self-perceptions, including self-advocacy, can also further promote normalization.

Pleasure and safety, couched in a discourse of normalization, fit well in a socially inclusive theoretical framework, as they acknowledge and work against barriers to doing (expression of sexuality) and barriers to being (acknowledgement of sexuality) (Thomas, 1999; Reindal, 2008). Together, safety and pleasure balance the need to protect potentially vulnerable

individuals from undue harm with the right to enjoy all aspects of their humanity. Consequently, sexuality curricula that integrate discourse of pleasure and safety help rebuke judgment (Finding 8, SB5), as well as promote socially inclusive outcomes. To borrow the words of one youth participant, the content of sexuality education has a “crooked balance” that needs to be readjusted to emphasize the positive outcomes of a healthy sexuality. Teaching these subjects requires recognition of the social and sexual rights of individuals with autism. In this sense, it normalizes their sexual and social lives, and is thus directly aligned with a socially inclusive perspective (Gougeon & Sénéchal, 2010).

**Sexuality education content: Final findings.** Put simply, the content of sexuality education, according to youth with high-functioning autism and their caregivers, as informed by the literature and as understood through a socially inclusive lens, can be conceptualized as being about knowledge—a necessary aspect—and behaviours—a sufficient aspect. In addition, it can be understood as including the dimensions of pleasure and safety, which, when equally balanced combine to form the construct of normalization. Having identified the overall content areas of sexuality education and discussed them in relation to the theoretical framework, I now turn to the main themes related to its form.

**Sexuality education: Modality.** Concerning form, sexuality education was seen as a multistakeholder endeavour. This view was shared by youth and caregivers, and was well supported by the literature. Though reported separately in the findings, responsibility for provision can be understood as linked with location of provision. In addition to responsibility, educator attributes were seen as an important aspect of sexuality education provision, with various attributes identified for prioritization. Finally, the ways in which sexuality education is delivered were also ascertained, and multiple perspectives were found. Consequently, the

subsequent section examines modalities of sexuality education according to the following main themes: situating sexuality educators and divergent perspectives of delivery. The section concludes with a review of these themes according to the theoretical framework.

**Situating sexuality educators.** Sexuality education was generally perceived as the responsibility of caregivers first and foremost (Finding 1, R1), followed by schools (R2). Such a view was shared by youth and caregivers, as well as in literature specific to autism (e.g., Ballan, 2012; Chan & John, 2012; Meister et al., 1994; Wolfe et al, 2009). Literature on the topic of sexuality education in general also supports the view that caregivers should be the primary providers of sexuality education for their children, with support from schools or community agencies (e.g., Allen, 1987; Blakey & Frankland, 1996; Constantine et al., 2007; National Foundation for Educational Research, 1995; Walker, 2004; Wyness, 1992). It was interesting to discover that youth generally viewed their caregivers as the *desired* primary providers of sexuality education. This differs in some ways from neurotypical adolescents. Research on sexuality education for neurotypical youth indicated that they ideally would like sexuality education to come from their caregivers, but in practice most feel that their caregivers are not comfortable or open to discussions, are not knowledgeable about current issues, or are judgmental (e.g., Angera, Brookins-Fisher, & Inungu, 2008; Somers & Paulson, 2000; Werner-Wilson & Fitzharris, 2001). One can hypothesize that youth with high-functioning autism may have been chastised (Finding 8, SB5), ridiculed, or bullied (SB2) by others because of their openness (Finding 5, IS1; IB5) and concrete thinking (IS4; IB3) in the past. Consequently, they saw caregivers as safe persons to approach about subjects related to sexuality (Finding 6, SS1), in contrast to peers or other less trustworthy adults who may not be as understanding toward them (Finding 8, SB5).

It would seem that caregivers saw themselves as the primary providers of sexuality education as a way of taking ownership of their child(ren)'s learning. That caregivers would be the primary providers of some aspects of sexuality education would make sense, as much of day-to-day living activities related to social and sexual learning (e.g., hygiene, privacy, boundaries, interpersonal relationships, and media exposure) take place in the home. Caregivers know their child best and in this sense are "experts" in their child's profile. Correspondingly, they may be able to provide relevant sexuality education that is appropriate to their child's strengths and needs (Finding 1, EA3).

Also, caregivers are experts in their family's values and are thus in the best position to provide this type of education to their children (McKay & Bissell, 2010; MEDU, 1998/2005, 1999, 2000, 2010a, 2010b), although this view is not unanimous, particularly when disagreements occur in family units (e.g., Sullivan & Caterino, 2008). For Findings 1 and 4, there were differing opinions regarding whose values should be favoured when determining the goals of sexuality education. Although none of the youth, almost half of caregivers, and some of the literature saw educational goals as something that should be aligned with family values (Finding 1, EA4), other textual sources supported privileging youths' values (EA5). It is likely that youth were not aware of their right and ability to advocate for curricular goals that may have been out of step with goals of their caregivers.

Relatedly, some extant literature advocated for value-based education to occur primarily with caregivers at home (Finding 1, R1). However, certain sources have proposed that all types of sexuality education are imbued with value (Halstead & Reiss, 2006; McKay & Bissell, 2010; PHAC, 2008), with PHAC stating: "Values and norms about sexuality and health come from a variety of sources including social and religious viewpoints, science, medicine and individual

experience” (p. 7). Some sources have proposed options to address values in sexuality education, including using formal-training opportunities for educators to make implicit values explicit to confront and challenge those which may be discriminatory (e.g., Agthe Diserens & Vatré, 2006; Hingsburger & Tough, 2002; Open Future Learning, 2012).

The sexuality education reported by caregivers tended to occur promptly and informally through critical incidents that took place outside of the classroom. This education was in addition to the more structured education reported by youth and caregivers that took place in schools. From a caregiver perspective, sexuality education transcended one location and one discrete curriculum (Finding 3, D3). In their experience, sexuality education occurred at the most unexpected (and often awkward) times. Many caregivers were thus unexpectedly engaged in the role of primary sexuality educator, whether they were prepared for it or not. From experiences shared in Finding 3 on critical incidents, the role of sexuality educator seems inextricably linked to being a caregiver.

Caregivers viewed themselves, and were viewed by others, as the primary sexuality educators for their children. Nonetheless, some expressed feeling uncomfortable or unprepared in this role (Finding 3), though these feelings did not generally impact the provision of sexuality education. Although caregivers reported being able to provide appropriate sexuality education, caregiver discomfort and lack of preparation have been documented in the literature (e.g., Ballan, 2012; Nichols & Blakeley-Smith, 2009; Ruble & Dalrymple, 1993) and attempts have been made to address this challenge through formal training (e.g., Nichols & Blakeley-Smith, 2009; Roth, 2009).

Arguably, the content of sexuality education needs to be differentiated for youth with high-functioning autism in ways that may be unfamiliar to caregivers. In this sense, caregivers

may know that their child learns differently and has different educational learning needs, but they may not have the tools or the know-how to provide adapted and effective sexual education. For example, many caregivers grappled with appropriate ways of dealing with issues of technology and sexuality. Some caregivers restricted their child's Internet access with parental controls, whereas others took away "inappropriate" video games. Some others had done nothing, being at a loss for what to do (Finding 8, SB3). The argument that caregivers do not have all of the requisite skills to support sexuality learning for their children with autism is supported by Ballan's (2012) research: "Parenting behaviors reflect insufficient effective strategies to foster the sexual and reproductive health and wellbeing of their children with ASD" (p. 682). As stated elsewhere, stakeholders can benefit from additional supports that fill gaps in knowledge, skills, or values (e.g., Blanchett & Wolfe, 2002).

In addition to lacking appropriate strategies, caregivers may not be aware of, or have access to appropriate resources. This may indeed be a legitimate issue, as caregivers identified lack of resources as an important external barrier to the provision of sexuality education (Finding 8, SB4). As demonstrated in Finding 4, some resources do exist specifically addressing the learning profiles of individuals with high-functioning autism (Attwood, 2008; Davies & Dubie, 2012; Hénault, 2006; Nichols et al., 2009). However, caregivers were largely unaware of these population-specific resources. Thus, lack of awareness of resources as well as limited access to them may be legitimate barriers to sexuality education provision. If caregivers lacked the necessary resources to provide adequate sexuality education to their children at home, it follows that youth likely did not have access to relevant resources at home either. This finding lends credence to youths' observation that lack of information acted as a barrier to their learning (Finding 8, SB1).

A need expressed by youth and supported by the literature (Finding 1, EA2) was that proficient sexuality educators need to have technical knowledge about sexuality topics; knowledge their caregivers simply may not have. However, this point was not supported by the survey findings, which indicated caregivers did have sufficient knowledge to support youth in their sexual education. To allow for some clarification, PHAC (2008) provided the following educator attributes as part of its guiding principles:

Those providing sexual health education have acquired through their training or equivalent experience: extensive general knowledge and understanding of human sexuality; knowledge and understanding of evidence-based approaches to sexual health education and promotion; specific knowledge of sexual health issues relevant to the audience, client group, etc.; the skills and confidence to act as effective sexual health educators in their professional setting; the ability to understand and acknowledge the needs of people of diverse backgrounds, sexual orientation, and varied sexual health education; the ability to sensitively affirm sexual feelings as a natural part of life; the ability to recognize the effect that religious, ethno-cultural and other variables may have on an individual's values and beliefs about sexuality; the ability to sensitively address and resolve conflicts that may arise as a result of differing values and beliefs surrounding sexual health and sexuality; specific understanding about issues related to sexual orientation and gender identity and skills to provide inclusive and nonjudgmental sexual health education in this area; sensitivity to gender-related issues relevant to sexual health; and media literacy relevant to sexual health. (p. 30)

This long list of attributes identified for sexuality educators in general, combined with the perceived content areas of facts, sociosexual norms, safety, pleasure, and normalization specifically identified for youth with high-functioning autism, may well amount to an impossible objective for caregivers, or any sexuality educator, to complete in isolation. Thus, although caregivers may want to provide sexuality education for their children, many may not have the resources, required knowledge, or expertise to do so appropriately. Perhaps for this reason, caregivers seek support from other sources such as school personnel, medical practitioners, or community organizations.

The role of the school in providing more formal sexuality education was generally viewed by youth and caregivers as important (Finding 1, R2), particularly in providing fact-

based information. Historically, as well, institution-based sexuality education such as in schools has provided information about facts and safety, while excluding or minimizing the content areas of sociosexual norms, pleasure, and normalization, because such topics are delicate and can be controversial. In this sense, formalized sexuality education has often emphasized what is forbidden while excluding what is permitted (Hingsburger & Tough, 2002). From a curriculum and policy perspective (MEDU, 2010a; PHAC, 2008), sexuality education in schools is evolving to be more inclusive of these traditionally neglected areas, though implementation of such policies and curricula is protracted. It would seem that addressing these content areas in schools would be appropriate, as school is where youth spend the majority of their weekday waking hours and where the majority of social, in addition to academic, learning occurs. Support for structured school-based sexuality education (Finding 3, D1), in addition to that offered at home, can be found in this statement by SIECUS:

While parents are – and ought to be – their children’s primary sexuality educators, they often need help and encouragement. Faith-based institutions, community-based organizations, and schools can play an important role. SIECUS believes that comprehensive school-based sexuality education should be part of the education program at every grade. Such programs should be appropriate to the age, developmental level, and cultural background of students and respect the diversity of values and beliefs represented in the community. Comprehensive school-based sexuality education complements and augments the sexuality education children receive from their families, religious and community groups, and health care professionals. (2004, p. 13)

This perspective supports the finding that sexuality education is an overarching activity that takes place in both formal and informal settings (D3). Also supporting the all-encompassing quality of sexuality education is PHAC’s statement:

Access to effective sexual health education requires ongoing support in both formal settings, such as schools, community groups, health and social service agencies and in informal settings where sexual health education is provided by parents, caregivers, peers and others. (2008, p. 18)

Despite support from theoretical, research, and practical school-based sexuality education, according to some caregivers, provision is not meeting all of their youths' needs (Finding 8, SB4). Whether sexuality educators are well-equipped to provide such a curriculum is unclear, as it was outside of the scope of this investigation. However, it is plausible that sexuality educators may not have the skills required to meet the educational needs of learners with different developmental profiles such as those with high-functioning autism. Such a hypothesis has been supported in research by Kalyva (2010), who found that most teachers do not feel able to provide adequate sexuality education for youth with autism. Thus, although school was conceptualized by youth and caregivers as an important provider of sexuality education, the content of school-based sexuality education may not meet the criteria identified by youth and caregivers (Finding 2, C1-C5), and informed by the literature. Also, it is unclear whether school-based educators have the requisite skills to provide sexuality education to youth with high-functioning autism (Finding 2, EA1-EA3) or otherwise.

In addition to caregivers and schools, community organizations were also considered by caregivers and the literature to be responsible for providing sexuality education (Finding 1, R3). Youth interview participants did not perceive community partners as potential educators, with only one youth mentioning them in this role (R3). This is especially relevant in the current context, as seven of the nine youth interviewed for this study were recruited via the ABA Services and Supports Program waitlist, indicating that most of these youth do not recognize the program as a potential provider of sexuality education. This may be due to their concrete thinking, which resulted in them having a narrower definition of sexuality education linked to their home and school experiences. It is also feasible that youth were largely unaware of the existence of community supports. Relatedly, it may be that community organizations do not offer

sexuality education for this population. Such a possibility would be in line with caregivers' posited external barrier that adapted resources are lacking, identified in Finding 8 (Finding 8, SB4).

Regardless of the underlying reason, this finding is not entirely surprising. Currently in the ABA Services and Supports Program, sexuality is only assessed as a need when it becomes problematic in ways that would prioritize it over other areas. As this program (and possibly others) currently stands, it acts as a barrier to effective proactive sexuality education. To become more socially inclusive through the provision of proactive and adapted sexuality education, the development of healthy sexuality must first be recognized as a legitimate goal in these settings. If healthy sexuality is not conceptualized as an important and developmentally appropriate goal, it may eventually result in reactive interventions to address resultant inappropriate sexual behaviours.

From a caregiver perspective, community organizations were seen as an integral part of the sexuality education team for their children. Collaborative relationships between community organizations/professionals, schools, and caregivers were also deemed mutually beneficial from a policy perspective:

School-community partnerships provide access to resources and services that can provide additional support to school staff, students, and families in the development and implementation of healthy school initiatives. Various organizations, including public health units, can collaborate with educators to deliver programs and services within the school setting. (MEDU, 2010a, 2010b, p. 8)

Community organizations, though in a separate setting (and perhaps because of it), may be able to provide more appropriate services tailored to the individual learning profiles of individuals with high-functioning autism. They may also have staff that is specially trained in areas of relevance to this population. Possibly, these staff may also be more understanding, accepting, and positive toward the sociosexual identities of these youth. In this sense, staff may be able to

act as supports in the manner described by youth and caregivers alike, being well-trained in sexuality topics (Finding 1, EA2), well-versed in the profiles of learners with high-functioning autism (EA3), and potentially trustworthy and inclusive (EA1).

Caregivers, schools, and community organizations were seen as responsible for sexuality education. To a lesser extent, youth themselves were sometimes identified in the literature and in policy as being agents of their own education (Finding 4, R5) (Hingsburger & Tough, 2002; MEDU, 2010a, 2010b; SIECUS, 2004). Caregivers and youth themselves did not raise the possibility of youth playing a role in their own education. Why this occurred is not entirely clear. It may be that youth did not perceive themselves as agents of their own education. Alternatively, youth may not have been aware of their own learning needs. Self-awareness in this population has been identified as a barrier in the literature (e.g., Mehzabin & Stokes, 2011; Mitchell & O’Keefe, 2008; Roth, 2009), and was reflected in the limited ability of some participants to enumerate strengths, supports, and barriers (IS; IB; SB). Possibly for this reason youth are limited in their ability to identify the need for sexuality education. Perhaps for this same reason, caregivers may have been indisposed to view youth as taking responsibility for their own sexuality education. Further, caregivers may have been fearful of youth seeking out sexuality education from inappropriate sources, particularly through unmediated use of the Internet (Finding 8, SB3) or through unhelpful peers (SB2). For the various reasons stated above, it is possible that youth and caregivers may have been unaware or reluctant to have youth take on their own sexuality education.

Although youth were not often mentioned as self-educators, peers were mentioned, but were generally viewed as inappropriate educators for youth with high-functioning autism (Finding 4, R4), though their role as a social support was more widely acknowledged (Finding 6,

SS3). According to research by Stokes et al. (2007), peers may not be effective educators to teach sociosexuality skills to youth with high-functioning autism because of the nature of their disorder:

[These youth] have less access to their peers and friends as sources of learning to acquire social and romantic skills and knowledge. This is likely a reflection of the core deficits characteristic of ASD itself, as impairments in communication and social reciprocity lead to greater difficulties in socialization and development of meaningful relationships. Although not surprising, this is problematic in that social learning from peers and friends is a significant predictor of overall social functioning. (p. 1978)

Youth with high-functioning autism need to learn from peers to improve their overall social success, but do not currently benefit from it. Thus, although peers may not be effective educators at present, it may be useful to explore ways of teaching youth with high-functioning autism how to learn from peers (e.g., Gougeon, 2009). In the interim, it would seem that peers do not generally provide efficacious education. It is possible that peer groups actually work against the effective provision of sexuality education in this population. For instance, some youth identified being bullied by others, due to their literal understanding of sexual concepts (Finding 8, SB2). Caregivers also reported bullying (SB2) and judgment (SB5) by peers as potential barriers to sexuality education. Peers may not be suitable educators for youth with high-functioning autism, but they may potentially be good supports if effective strategies are developed and implemented. In summary, sexuality education for youth with high-functioning autism may be viewed as a shared responsibility, with caregivers first and foremost, followed by school and community partners. Thus, it is both a formal and an informal activity that takes place across various settings.

**Divergent perspectives of delivery.** Regarding the delivery of sexuality education, the primary topics of discussion were those of group versus individual delivery, gender/diagnosis groupings, and location of delivery. The location of delivery was related to curriculum provision.

Nevertheless, the location of sexuality education is also closely connected to who is responsible for providing it. Consequently, this aspect of sexuality education was addressed in the previous section. In the same way, timing of curriculum delivery was reported as part of Finding 2, which related to content. However, its relevance to sexuality education at a deeper level is better aligned with the facet of curriculum delivery. Accordingly, this finding is addressed in this section.

Overall, although there was no consensus regarding delivery (Finding 1, P1-P3), it would appear that a mix of individual and small-group delivery founded on individualized goals may be the most appropriate modalities of sexuality education for youth with high-functioning autism (P2). Research emphasized individualization (P3), though it is conceivable that individual provision implied individualized goals and/or teaching strategies in a group setting. Because of the nature of autism, content requires individualization to meet the needs and strengths of each individual. Thus, learning goals use identified internal and external supports to meet individual needs (e.g., Griffin-Shelley, 2010; Ruble et al., 2012). This was the argument used by curricula developers in the field (Davies & Dubie, 2012; Hénault, 2006; Nichols et al., 2009). Such a stance reflects best practice in the field of autism (e.g., Gulick & Kitchen, 2007; Simpson, 2001; Wolfe et al., 2009), and in education more generally (MEDU, 2010a, 2010b; PHAC, 2008).

Furthermore, because many content areas of sexuality education identified as part of this study are intimately linked to social skills, it is essential to provide this education with others, whenever appropriate and feasible to do so. At the same token, there are personal topics that may best be addressed on a 1:1 basis and in private (e.g., critical incidents reported in Finding 3). Finally and perhaps most compelling is the argument that youth desire learning (partly or fully) in a group setting. In the absence of evidence to the contrary, youth preference for curriculum

delivery should perhaps take precedence over other views. This interpretation is upheld at a local policy level, with the MEDU asserting that educators should “consult with the student about his or her needs and about choosing strategies that will help him or her feel comfortable and included” (MEDU, 2010a, 2010b, p. 51).

Another dimension related to curriculum delivery was that of gender groupings. Caregivers and youth disagreed on whether youth should be taught in a mixed-gender group, in a segregated-gender group, or in a mix of both segregated and combined settings. Caregivers generally supported a combination of segregated and mixed genders (Finding 1, P3), whereas most youth preferred mixed-gender teaching (P4). Some youth were cognizant and respectful of the view that their peers may not be as comfortable as them and were open to the possibility of segregating genders to accommodate this discomfort. Such a finding was surprising as it demonstrated these youths’ ability to perceive discomfort in others, an empathetic attribute not commonly associated with individuals on the autism spectrum. This finding was congruent with some caregivers’ perceptions of empathy in their children (Finding 5, IS3). There was no agreement about gender groupings between youth and caregivers; similarly, no agreement was found across textual sources. As was exposed in Finding 4, opinions were divided even among experts on sexuality education for individuals with high-functioning autism. Some advocated for partly to fully segregated gender groupings (IS3) (Nichols et al., 2009; Roth, 2009), whereas others advocated for mixed-gender groupings (IS4) (Davies & Dubie, 2012; Hénault, 2006). No research was found to have empirically validated one modality over another for this population. In the absence of evidence, the most persuasive argument points to respecting the preferences of youth themselves.

A third feature related to the delivery of sexuality education investigated in this study was the timing of content presented to youth with high-functioning autism. This theme did not emerge with youth but was raised in interviews with caregivers (Finding 2, C6). Most caregivers expressed a need to modify the timelines of content delivery to meet the delayed developmental maturity of their child(ren). The need to strike a balance between developmental and physical maturity was well supported in the extant texts (C6). However, as exposed in Finding 4, the literature clearly articulated that adaptations to content delivery timelines must not sacrifice the timeliness of provision (C7). Proactive delivery of sexuality education is well supported in literature in the field of disability, having been linked with improved personal social and health outcomes (Craft, 1994; Di Giulio, 2003; Lawson, 2005; Sobsey, 1994). In literature related to autism, timeliness of delivery was explained as sexuality education provided proactively and starting at a young age (e.g., Ballan, 2012; Gerhardt, 2006; Koegel & LaZebnik, 2009; Mitchell, 2010). Determining when to provide adapted sexuality education that is at once delayed and proactive for each individual child can be challenging. Research in this area has demonstrated that youth with high-functioning autism are not homogenous when it comes to sexuality, as revealed in Stokes and Kaur's finding: "high variability within adolescents with HFA [high-functioning autism] on sexual behaviour is congruent with the diversity in this population's clinical presentation" (2005, p. 280). Their work adds further credence to the difficulties inherent in appropriately adapting formal sexuality education.

In light of these disparate educational needs, providing some of the formal components of sexuality education for youth with high-functioning autism in a separate setting may be warranted. The opinion that (partly or fully) separate sexuality education may be beneficial was held by the majority of caregivers. For their part, youth did not explicitly reveal a preference of

educational environment for their sexual learning needs. However, experiences of bullying in inclusive settings (Finding 8, SB2) may be viewed as implicitly supporting the partial provision of formal sexuality education in a separate environment. Additionally, youths' identification of limited access to meaningful information as a barrier (SB1) may also provide partial support for separate formal education, particularly if such a curriculum would provide them with information they were able to correctly apply in daily life.

At a policy level, no explicit support was found advocating for separate provision of sexuality education. However, Autism Ontario has supported a range of more or less inclusive education-placement options, based on student need (Autism Ontario, 2007). From research and practice perspectives, separate provision of sexuality curricula is well documented. Published curricula by Hénault (2006) and Davies and Dubie (2012), for example, are meant to be provided in a separate environment unique to individuals with high-functioning autism. Similarly, research on sexuality education interventions for this population has focused on provision in a separate setting (e.g., Hatton & Tector, 2010; Nichols & Blakeley-Smith, 2009; Roth, 2009; Tissot, 2009). Thus, provision of an adapted curriculum in a distinct setting is well supported in the literature.

**Sexuality education modality and the theoretical framework.** Sexuality education was seen as a multistakeholder activity that took place across formal and informal settings. Caregivers were seen as primary providers of ad hoc sexuality education, whereas school and community partners were generally seen as providers of planned curricula. Understood through a socially inclusive lens, these various sources of formal and informal education can act as supports in the provision of meaningful sexuality education that leads to better long-term social outcomes (e.g., Renty & Roeyers, 2006). These external supports can compensate for social and

communicative impairments (e.g., Finding 7, IB1-IB4) experienced by youth with high-functioning autism that may otherwise prevent them from benefiting from informal forms of sexuality education (e.g., through the hidden curriculum). As discussed in the previous chapter, individuals with high-functioning autism may not be appropriate self-educators due to their impairments. However, increased self-awareness through targeted training could support the development of self-advocacy skills that would allow these individuals to better seek appropriate sources of sexuality education.

Although caregivers were identified by others, and self-identified as primary providers, there was evidence that they may, to some extent, lack some of the necessary skills and resources to properly support their child(ren). Other providers may also lack some of the skills, comfort, or resources to provide appropriate sexuality education to youth with high-functioning autism. However, when combined, caregivers, schools, and community partners may have most of the skills and resources necessary to meet the educational goals of these youth. Fundamentally, trustworthiness was viewed by youth and caregivers as an important characteristic for any sexuality educator (Finding 6, SS1). From a socially inclusive perspective, peers may not be appropriate educators, as they may not have the information (C1-C6) or skills (EA1-EA4) required to provide adequate education. Nonetheless, well-informed and willing peers could help support the generalization of related skills learned by youth with high-functioning autism acquired in more formalized settings (SS3).

Youth and caregivers generally agreed on content, though topic emphases were different. As seen above, there were also marked differences of opinion toward provision. As previously discussed, some sources proposed formal training as a means of confronting and transforming value incongruence (e.g., Agthe Diserens & Vatré, 2006; Hingsburger & Tough, 2002; Open

Future Learning, 2012). Additionally, in situations where disagreements arise regarding curriculum content, provision, or acceptability of individual behaviour, using a set of questions to explore stakeholders' underlying assumptions can be helpful to promote socially inclusive discussion (Gougeon, 2010). Addressing these disagreements and their underlying assumptions, in turn, can support the collaborative development of learning plans created through communication with all stakeholders, to ensure that youths' needs and strengths are met; such a view is supported in the literature (e.g., Autism Ontario, 2006; Bennett & Wynne, 2006). A familycentric approach, aligned with a socially inclusive framework, sees the child at the heart of decisions and delivery of services, while also recognizing the role of the family in these services. It is also founded on a shared vision built around the child and family's strengths and needs, and contextualized by their culture, values, and environment (Gougeon, 2011). Furthermore, a family-centred approach is founded on the provision of services by caring and competent stakeholders (Athanasiou, Geil, Hazel, & Copeland, 2002; August et al., 1992; Cook, 2005; Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Gougeon, 2011; Perrin et al., 2007; Rebeiro, 2000; Shelton & Smith Stepanek, 1995), attributes recognized by caregivers and youth, and supported in the extant literature (Finding 1, EA1-EA3). Such a socially inclusive view does not divide additionality (caregiver and stakeholder input into goals/provision that may be missed by youth due to the nature of their impairment) and inclusivity (youth preference). Empirical evidence and youth preference can be combined, allowing for decisions about content and provision that can ultimately support socially inclusive outcomes.

Along with who should be responsible for sexuality education and what their attributes should be, how sexuality should be provided was also investigated. Overall, no consensus was found regarding the various facets of sexuality education delivery. Caregivers, youth, and the

literature differed on the topic of group versus individualized delivery, though arguments in favour of developing individualized goals for a mix of individual and group-based curriculum seemed to be most compelling. Gender groupings also met with disparate opinions across all sources, though support for mixed groupings seemed more appropriate. In particular, that sexuality education should be provided in a group, mixed-gender setting is better aligned with a socially inclusive perspective, as it respects the preferences of youth themselves. This is all the more relevant with a lack of evidence to the contrary. Such an approach is squarely aligned with a socially inclusive theoretical framework, as it is one way of acknowledging how disability acts as a barrier to being (Thomas, 1999). Recognizing the voices of marginalized groups is one way of pushing back this barrier to being (Worth, 2012).

Finally, support for providing developmentally appropriate, yet proactive sexuality education, potentially in a separate setting, implicitly emerged as part of this study through youths' experiences, explicitly through caregiver interviews, as well as pervasively across theoretical and applied literature. From a theoretical perspective, an argument can be made for sexuality education that takes place across multiple settings, especially in accordance with the ways described in this study. The primary location of sexuality education was seen as occurring at home with caregivers. As revealed in the findings, this informal sexuality education is responsive and timely, though incomplete. A second location for more formal sexuality education was seen as occurring in school. This was demonstrated to be an important and integrated location for education to take place with peers, though its contents did not meet all of the educational needs of youth. Finally, a third location for formal and adapted sexuality education was seen as occurring in community-partner locations. I advance that the provision of sexuality education in such a setting can potentially mitigate the physical exclusion that would be

experienced if such a curriculum was provided in a congregated school setting during school hours, while also addressing the learning needs of youth with high-functioning autism.

**Sexuality education modality: Final findings.** In summary, according to youth with high-functioning autism and their caregivers, extant texts, viewed through a lens of social inclusion, sexuality education can be conceived as a shared responsibility between various trustworthy adults: caregivers first and foremost, as well as school and community partners. Educators may benefit from possessing relevant knowledge and skills in the areas of sexuality and autism, as well as technology. Correspondingly, it can be both a formal and an informal activity that takes place across various settings. Along this same vein, sexuality education can be comprised of both 1:1 and small-group delivery, in mixed- and separate-gender groupings, and in inclusive and separate settings according to diagnosis. Provision may best meet the needs of youth when it is adapted to their developmental and physical realities. Decisions may be best achieved through familycentric, multistakeholder communication. Having reviewed the first two research questions, I will now analyze and interpret the main themes surrounding supports and barriers to sexuality education that emerged in response to Research Question 3.

### **Research Question 3**

**Supports and barriers to sexuality education.** In addition to creating a conceptual framework of sexuality education, I looked at the supports and barriers to sexuality education perceived by youth and their caregivers. Personal facilitators and barriers were identified, along with social/societal ones. Most of the supports and barriers identified as part of this study were incorporated in the discussion of sexuality education conceptualizations of the previous two sections, revealing areas of strength and support, as well as areas of need in sexuality education content and delivery. However, one theme emerged from the supports and barriers themselves that bears further examination on its own. Among the many supports and obstacles put forth,

some could act in supportive or obstructive manners. Also, some appeared more definite in their attribute of either support or barrier. Correspondingly, the ensuing section examines barriers and supports according to the key theme of stability and fluidity. I conclude this section with a discussion of these themes in light of the theoretical framework.

**Stability and fluidity of supports and barriers.** Overall, youth were less able to identify supports and barriers, both internally and externally. Caregivers were more articulate regarding facilitators and barriers to their child(ren)'s sexuality education. Many facilitators and obstacles identified by youth and caregivers were presented in a categorical manner. That something was a strength or support was generally seen as unchanging, regardless of context. For example, intelligence (Finding 5, IS2) and empathy (IS3), as well as trusted adults (Finding 6, SS1) and supportive peers (SS3) were all largely seen as facilitators to accessing sexuality education. Interestingly, affective empathy was identified by over half of caregivers as a positive personal attribute, a finding that is contrary to the general perception of individuals with high-functioning autism (e.g., Baron-Cohen, 2001; Baron-Cohen & Wheelwright, 2004; Griffin-Shelley, 2010).

Similarly, most barriers itemized by participants were seen as wholly negative. Among these obstacles were delayed developmental maturity (Finding 7, IB4), lack of peers/bullying (Finding 8, SB2), unresponsive resources (SB4) and judgment (SB5). These were discussed at length as part of the previous findings, and were seen to be well supported by previous research. In particular, judgmental views toward the sexuality of individuals with high-functioning autism were well documented in the literature review of this study (Hellemans et al., 2007; Realmuto & Ruble, 1999; Tissot, 2009; Van Bourgondien et al., 1997) and elsewhere (e.g., Galluci et al., 2005; Griffin-Shelley, 2010).

Low self-perception was only elicited by a few youth and no caregivers, however it is possible that others also saw themselves negatively but did not report this view. This hypothesis is supported by the finding that all youth struggled to identify personal attributes that could act as supports to accessing sexuality education (Finding 5, IS), although they did not struggle to the same extent in identifying other supports or obstacles (Finding 6, SS; Finding 7, IB; Finding 8, SB). It is conceivable that youth simply did not comprehend the questions regarding personal strengths associated with sexuality education. However, as youth were better able to identify personal barriers to sexuality education, it would seem unlikely that they understood questions about personal barriers but not about personal strengths. Negative self-perception is consistent with previous research conducted with this population (Hatton & Tector, 2010; Hénault & Attwood, 2004).

Whereas most of the facilitators and obstacles elicited as part of this study were viewed as unwavering in their categories, some were found to act as supports in one setting and as barriers in another. In this way, certain items were especially context-dependent. In particular, openness was seen as both a facilitator and a barrier to sexuality education by caregivers, depending on the context. Openness was seen as a double-edged sword in that it allowed for sexuality topics to be discussed openly and without embarrassment. However, such openness could result in youth discussing topics at inappropriate times, which could cause discomfort in others or result in being chastised, teased, or bullied. Such a conclusion is supported by the external barrier of bullying identified by youth and caregivers (Finding 8, SB2), or judgment identified by caregivers alone (SB5).

One way in which openness and lack of embarrassment were clearly observable was during interviews with youth. Fully six of the nine youth participants chose to have their

caregivers present or in close proximity during their interview. This was a surprising and unanticipated discovery of this study. Indeed, in conceiving of this project and in completing the ethics process, a private interview location for youth, away from caregivers, was deemed most appropriate (and logical from an etic perspective). However, most youth actively requested the presence and participation of their caregivers. For those youth who were interviewed privately, one youth left the room to consult with his caregiver on multiple occasions, whereas another youth promptly explained to his caregivers what had been discussed following the interview. Thus, out of nine youth, only one actually had what could be deemed a “private” interview. That youth with high-functioning autism are generally comfortable and emotionally detached from discussions about sexuality is consistent with the literature (e.g., Hatton & Tector, 2010; Hénault, 2006).

Another attribute that was seen as both a support and a barrier was concrete thinking (Finding 5, IS4; Finding 7, IB3). Youth tended to have sharply delineated views of issues related to sexuality. Such a finding was unsurprising, as it is consistent with autism spectrum disorders (Lawson, 2005). Concrete thinking was particularly relevant to the content area of sociosexual norms (Finding 2, C2). Thinking in concrete ways acted as a facilitator for teaching conventional and unconventional behaviours, according to a family or school board’s particular values (e.g., using condoms, abstinence until marriage, not drinking or smoking, and avoiding drugs). Youth tended to internalize these views and held them quite strongly. Although these attitudes may have been helpful in guiding their behaviour through some aspects of adolescence, concrete thinking could limit their ability to manage more ambiguous situations. The limitation of concrete thinking is sometimes also associated with an inability to generalize specific examples to a more global context. It is also often closely linked to the attribute of openness. In this

manner, most youth wanted to be told specific behavioural rules pertaining to sociosexuality such as timelines. For example, one youth wanted to be told when he would get a girlfriend (Jeremiah). Some youth expressed their interest in explicitly being told what was acceptable and unacceptable with regards to sexuality. Certain social and sexual behaviours are always open to interpretation and therefore cannot be taught in a completely discrete manner. In other words: Some sociosexual norms cannot be fully task-analyzed.<sup>11</sup> Thus, while certain sociosexual norms can be reduced to some behavioural rules, other norms are more complex and nuanced and require teaching a wider skill repertoire that is applicable in a broader context.

Another attribute that was seen as both a strength and an obstacle by caregivers was sensory issues/attention (Finding 7, IB2). Although sensory issues were not explicitly mentioned as personal strengths, most likely because they were not seen to directly impact sexuality education, caregivers did mention youth sensory particularities as strengths. For example, auditory sensitivity could act as a barrier to learning in a noisy classroom environment; that skill translated into giftedness in music for some youth. Similarly, deficits in attention, which acted as barriers when attending to lecture-based learning, translated into many of these youth being very competent at video games or other technological activities.

One item that was labeled a support by youth and a barrier by caregivers was the Internet/other media (Finding 6, SS2; Finding 8, SB3). Youth perceived access to the Internet and other media as a potential support in learning about sexuality education, though many youth were cautious in the sources that were accessed to this end. This finding supported youths' identification of a lack of information as an obstacle to their sexuality education (SB1). In a way, the Internet and other media could help bridge the sexuality-information gap. Caregivers viewed

---

<sup>11</sup> "Task analysis" is the process of breaking down complex skills or behaviours into their smaller teachable parts (Cooper et al., 2007).

unmediated access to the Internet and other media as a barrier. Specifically, caregivers were concerned that youth were accessing inaccurate information (e.g., unreliable websites), accessing inappropriate content (e.g., pornography), or were putting themselves at risk (e.g., via online sexual predators). In addition, caregivers were concerned that the content accessed without adult mediation would result in youth erroneously thinking it reflected reality. Indeed, discussions about the Internet or other media and technology (e.g., video games or television) permeated all interviews. As one caregiver commented, the availability of smart phones meant that youth had access to portable Internet that could not easily be controlled (John). Moreover, some youth demonstrated compromised safety skills when accessing the Internet or when using other media/technology.

Literature on the subject has been mixed. A study by Mehzabin and Stokes (2011) found that adults with high-functioning autism do rely on media (television) as a source of sexuality education, whereas another source provided the following advice: “Make sure that you have good Internet protection as pornography is easily obtained and distorts young people’s views on sex” (Moxon, in Middletown Centre for Autism, n.d., p. 6). Although perhaps accurate in its claim that some types of pornography distort views about sex, this suggestion is limited in its applicability and usefulness. As expressed by caregivers in this study, parental controls demonstrated limited effectiveness in curbing youths’ inappropriate online activity. In a society where pop culture and porn culture are increasingly blended, this reality is concerning (Palmer, 2012). Other sources have been more pragmatic in their assessment of the situation. PHAC (2008) offered the following view on media in sexuality education:

Since the media plays a major role in the sexual education of individuals, effective sexual health education provides training in critical media literacies to help individuals identify and deconstruct hidden and overt sexual messages and stereotypes. Importantly,

comprehensive sexual health education helps individuals to understand how these messages may affect their sexual health. (p. 25)

Such an approach may be more beneficial in supporting youth in their navigation of sexuality topics through various media and technologies. Likewise, both versions of the updated provincial Health and Physical Education Curriculum (MEDU, 2010a, 2010b) address safe technology use in a variety of ways, including Internet and cell-phone use, and video games, and by addressing issues such as cyberbullying. However, the interim document does not address sexting, whereas the complete version does, by means of the teaching exemplar provided below:

Teacher prompt: “Sexting – or the practice of sending explicit sexual messages or photos electronically, predominantly by cell phone – is a practice that has significant risks. What are some of those risks?”

Student: “Photos and messages can become public. They can be manipulated or misinterpreted. If they become public, they can have an impact on future relationships and even jobs.” (MEDU, 2010a)

Such a curriculum could help explicitly teach youth the risks and benefits of using different media and technology, and also openly teach safe ways of using these different tools. Again, this curriculum has not yet been fully implemented.

**Supports and barriers to sexuality education and the theoretical framework.** The supports and barriers garnered from this study were best understood through a socially inclusive framework. At the same time, they also helped to further understand and refine the framework. Some expected and some surprising findings emerged with regards to the supports and barriers to sexuality education. Empathy was one of the more enlightening findings. Caregivers provided compelling arguments in support of their child(ren)’s empathy. These discussions of empathy actively resisted the prevalent discourse to the contrary. As such, they were rooted in a social-relational theorization of disability where impairment and social constructs of disability are unpacked and exposed. These discussions were particularly apt and poignant as they occurred in

the weeks following the Newtown, Connecticut (USA) tragedy<sup>12</sup>. Viewed through a socially inclusive lens, providing training to peers and educators to uncover the myths associated with autism could help address some of the external barriers identified in this study. For example, training could decrease judgment of these youth (Finding 8, SB5). This deeper understanding may result in increased acceptance and decreased bullying by others (SB2), though the efficacy of antibullying intervention programs would need to be established first (e.g., Rawana et al., 2011).

Although only a third of youth reported negative self-perception as a personal obstacle, it is concerning that caregivers were not aware of this personal barrier. Using a socially inclusive theoretical lens, it is possible to expose negative self-perception as a disabling consequence, rather than an actual impairment. This is because negative self-perceptions, although more prevalent in individuals with autism than in neurotypical individuals (Hatton & Tector, 2010; Hénault & Attwood, 2004), are not part of the diagnostic criteria that defines autism. Thus, the theoretical lens reveals poor self-concept for what it is: the consequence of disabling social and societal barriers. Nonetheless, from a socially inclusive perspective, it may be important to include work on self-identifying personal strengths and ways to incorporate these strengths into useful behavioural repertoires. This approach is supported by the COMPASS model (Ruble et al., 2012) and is a component of at least one curriculum in existence for this population (Hénault, 2006).

Overall, supports and barriers were seen as binaries. However, the view that some personal attributes can act as both strengths and barriers has been supported by the literature (e.g., Frith, 1989; Happé, 1999; Ruble et al., 2012). Some have argued that autism does not

---

<sup>12</sup> On December 14, 2012, Adam Lanza shot and killed 20 children and 6 adults then took his own life at Sandy Hook Elementary School. Lanza was 20 years old and diagnosed with Asperger syndrome (Koughan, 2013).

create a deficient mind, but a different mind, with needs and strengths often stemming from the same origin (Frith, 1989; Happé, 1999); these conceptualizations of autism concord with the openness, literal thinking, sensory, and attention examples provided by caregivers. From a socially inclusive perspective, recognition of attributes understood as barriers having the potential to act as supports may result in increased valuing of individuals with high-functioning autism in society (Aylott, 2000).

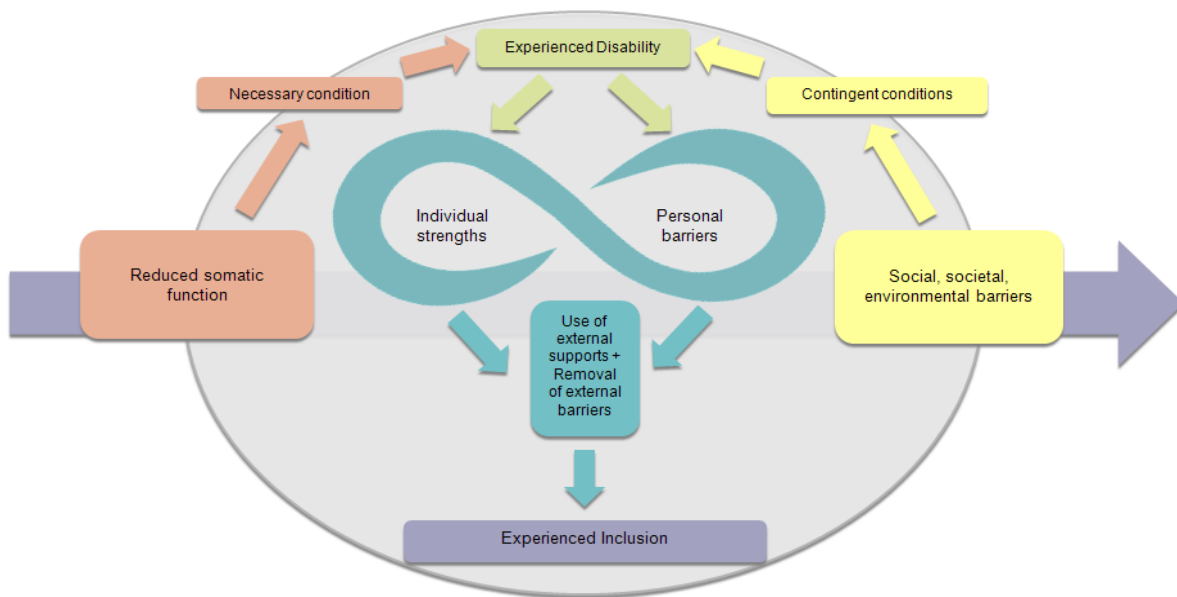
As identified by caregivers, the contentious issue of media and technologies is youths' unsupervised access because caregivers perceived youth as lacking the requisite skills to safely or appropriately navigate these tools. At issue with caregivers, then, were not the media and technologies per se, but youths' lack of skills. Arguably, access to media and technology are essential in promoting the social inclusion of these youth. It follows that teaching safe and critical media/technology use as part of a sexuality curriculum for youth and caregivers may be warranted, and would fit squarely in a socially inclusive perspective, particularly if such an approach adopted the information-application approach identified as part of Finding 2.

**Supports and barriers to sexuality education: Final findings.** In brief, various supports and barriers were put forth by youth and caregivers. Through a socially inclusive lens, these were understood at a deeper level. For example, one personal attribute, empathy, challenged the discourse of disability. A personal barrier, low self-perception, was exposed as a consequence of environmental obstacles rather than a true personal barrier. Some supports and barriers were seen as static, others were conceptualized as being more fluid. In particular, the traits of openness, literal thinking, sensory particularities, and attention, which are closely associated with autism, have the potential to be viewed as strengths in addition to barriers. In

light of these findings, the theoretical framework developed for this study was further refined. It is to this topic that I now turn.

### **Socially Inclusive Theoretical Framework Revisited**

Taken together, the findings and their analyses present a picture of sexuality education and its supports and barriers, as identified by youth and caregivers, and as supported by the literature, that fits faithfully in a socially inclusive framework in all but one area. The discovery that some items could be viewed as both supports and barriers did not fit with the discrete categories presented in the framework proposed at the outset of this study. In light of this information, the theoretical framework has been adapted to reflect this outcome (see Figure 9).



*Figure 9.* Revised hybrid theoretical framework of social inclusion.

## **Summary of Final Findings**

Sexuality education is a multifaceted concept that does not have one universal meaning. However, some aspects of sexuality education garnered from various sources in this study and relevant to the specific context of this study can be identified. First, the content of sexuality education can be conceptualized as being about the necessary aspect of knowledge, and the sufficient aspect of behaviours. It can also be understood as being about pleasure and safety, which combine to encompass the overall normalization of sexuality for these youth.

Caregivers can be viewed as the primary providers of informal sexuality education, supported by more formal curricula through school and community partners. Educators may benefit from possessing certain key attributes, such as relevant knowledge and skills in the areas of sexuality and autism, as well as technology, with each source of sexuality education potentially providing its unique contribution. Sexuality education can take on the form of formal and informal learning opportunities; these can take place across various settings. It may involve a mix of individual and small-group delivery, with a focus on individual goals. It can also be provided in mixed- and separate-gender groupings, and in inclusive and separate settings according to diagnosis. Adaptations to the curricula may be made to best provide for the developmental and physical needs and strengths of the individual. Decisions may be best achieved through familycentric, multistakeholder communication, as supported by evidence in the field.

Many supports and barriers exist in relation to sexuality education. Most of these can be viewed as static; however some attributes may be somewhat fluid. For example, some personal attributes may be considered assets in one context and liabilities in another. Personal traits such as empathy may exist in individuals with high-functioning autism that challenge previous notions of this disability. Personal strengths and external supports may be of use in overcoming personal

barriers and external obstacles to sexuality education. Having completed the analysis, interpretation, and synthesis of the findings, the proceeding section provides some practical suggestions, limitations, and contributions of the research, as well as some concluding remarks.

### **Suggestions**

As a result of the final findings put forth above, some suggestions that flow from these assertions may be of value to practitioners, policymakers, and researchers. These suggestions are presented below.

#### **Suggestions for caregivers, educators, and curriculum developers:**

- The development of an outcomes-based curriculum founded on facts and skills, including content on safety, shared enjoyment, and the development and application of strengths, would be of benefit to youth with high-functioning autism. Further, because technologies are in constant evolution, curriculum that focuses on healthy behaviour-based skills to navigate media and technology rather than on technology-specific skills would be particularly useful. Ongoing revisions and updates of such a curriculum would ensure its lasting relevance.
- Various stakeholders may benefit from further training to address their gaps in knowledge and skills, as well as limiting attitudes. In particular, educators may gain from acquiring knowledge of autism and effective teaching strategies, knowledge of sexuality, and current critical technology and media skills. Peers could also benefit from behaviour-based, socially inclusive antibullying training to enhance their supportive role.

#### **Suggestions for policy analysts, educational leaders, and program administrators:**

- The updated (2010) Ontario Health and Physical Education curriculum for Grades 1–8 should be reimplemented in its entirety.
- Increased awareness of sexuality resources and services available for individuals with high-functioning autism is needed. This could be accomplished through the creation of a web-based resource list and public access to a lending library.

**Suggestions for future research:**

- In line with the discovery that most youth in this study preferred being interviewed with their caregiver(s), future research could employ case-study methodology to allow for in-depth comparisons across youths and caregivers in family units.
- As all the youth interview participants were male and sex differences have been identified in the profiles of individuals with autism (Nichols et al., 2009), future research could investigate sexuality education with female youth who have high-functioning autism.
- Future researchers may want to explore educator or community-partner perspectives on sexuality education for this population.
- Future applied research should verify the efficacy of mixed- versus segregated-gender groupings, as well as individual versus group delivery of sexuality education for this population.
- As the tools employed were created or adapted specifically for this study, further research will be needed to demonstrate their usefulness and trustworthiness outside of the current setting.

**Suggestions for qualitative research strategies with this population:**

- Researchers engaging in qualitative research in the future with individuals with high-functioning autism may want to adapt their interviewing techniques to ease participants' anxiety and social uneasiness. One strategy that was found to be effective when available was interviewing youth while they were otherwise engaged in an enjoyable activity that required minimal eye contact with the researcher (e.g., using the computer).
- Researchers engaging in future research with individuals with high-functioning autism may want to prepare adaptations to open-ended questions such as topic lists participants can choose to expand on.

### **Limitations**

There were some notable limitations to this study, one of which was inherent to qualitative approaches in general, whereas others related specifically to this project. A limitation inherent to qualitative research methodology is that of researcher subjectivity. As stated throughout this study, the interpretations presented reflect the meanings I inferred from the various data sources. However, I attempted to limit bias in my interpretations by seeking to give equitable voice to youth perspectives, including those who were less articulate. For each finding, I sought divergent examples. I also contextualized the research to prevent holistic bias. Finally, I engaged in critical reflection throughout the research process, and attempted to periodically bracket my personal experiences, assumptions, biases, and theoretical stance during the analysis and synthesis of the data (Creswell & Miller, 2000; Gearing, 2004; Tufford & Newman, 2012)..

Specific to this study, self-selection may have biased the findings in a certain direction. For example, caregivers in this study may have been more open and accepting of their child(ren)'s sexuality than the rest of the population, which may have biased the results. In

contrast, caregivers with children experiencing significant sexual issues may also have self-selected to participate in this study, thereby biasing the results in another way. A related limitation was that no youth opted to participate in this study independent of their caregiver(s). Consequently, although in theory youth were free to participate in this study on their own, in practice this was not the case.

Also specific to this study, the small survey sample size limited the types of analyses that could be conducted with the data and reduced the power of the statistical tests that were performed. In addition, some interview participants chose not to complete the survey portion of the study, limiting the information available for analysis and comparison with data from other sources. As a result of this small response rate, data from the surveys were used to support the interview portion of the study. Another limitation of this study was that all youth interview participants were male, and all but one of the youth survey participants were male as well, restricting the inferences that could be made from the data. Another limitation specific to this study was the lack of educator/community-partner voice, as their perspectives would have contributed to a more complete picture of the subject. Finally, due to the way this study was structured and to protect participant privacy, comparisons among family members could not be made. From a methodological perspective, case-study methodology may have allowed for a deeper understanding of sexuality education, as conceptualized in family units.

### **Contributions**

This project contributes in theoretical, empirical, practical, and meaningful ways. I discuss these contributions individually below.

**Theoretical.** This project makes an important contribution to theory in that it provides a way of conceptualizing sexuality education that draws from prior models of disability (Norwich, 2002; Reindal, 2008; Thomas, 1999) and competence (Ruble & Dalrymple, 2002; Ruble et al.,

2012) but is different in that it is socially inclusive. The sexuality education iteration of the innovative hybrid (disability, education, and autism) socially inclusive framework created in 2011 had some of its parts augmented, including in the areas of content and modality. Moreover, both the specific sexuality education and overall social-inclusion frameworks were further elaborated and refined to reflect the nuanced supports and barriers discovered as part of this research project. These refined frameworks help broaden theoretical discussions that can potentially translate into practice that is more socially inclusive.

**Empirical.** From an empirical standpoint, this study contributes in a unique way by furthering understanding of the subject investigated through the development of a novel sexuality education conceptual framework specifically for youth with high-functioning autism. By using a qualitative approach with youth with high-functioning autism, this study addressed a gap in the literature by consulting youth directly and obtained profound insight on the topic, inaccessible through quantitative measures employed on their own (Hatton & Tector, 2010; Mehzabin & Stokes, 2011). It also provided further understanding into the personal and societal barriers that hinder sexuality education. More importantly, however, it identified personal strengths and external supports, in addition to personal and external barriers. This combined knowledge offered a deeper understanding of sexuality education in its lived context. Also from an empirical standpoint, this study demonstrates that research on a sensitive topic with a doubly vulnerable population can be conducted with respect and dignity, and can produce significant knowledge. The tools developed, adapted, and translated as part of this project can be used in future research endeavours in the areas of autism and sexuality education. It is hoped that the findings from this study will motivate others to pursue research that expands knowledge and understanding of the

topic. Possibilities for combined quantitative ABA-based intervention and qualitative social-validity-assessment research seem particularly promising.

**Practical.** From a practical perspective, the results obtained through this study can be used to inform program and curriculum development for youth, caregivers, schools, and community partners. These results could also potentially be used to provide input into policy development in the field of sexuality education, autism, and inclusion. In addition, some of the resources that were discovered through this research project may be of use to youth, their caregivers, and educators. Correspondingly, along with a summary of the study's findings, which will be sent to all interested participants and other stakeholders, a list of updated relevant resources will be shared with participants.

**Meaningful.** This project contributes in a meaningful way in that it allowed for the voices of individuals who have historically been excluded from research to be heard. It also allowed for the voices of caregivers to be heard, providing what I hope was a balanced view on the topic of sexuality education for youth with high-functioning autism. That youth, caregivers, and other stakeholders who are seeking insight and validation may find some in this study provides meaning to this work.

### **Final Thoughts**

*Behind the hieroglyphic streets there would either be a transcendent meaning, or only the earth. . . . Another mode of meaning behind the obvious, or none.*

—Thomas Pynchon, *The Crying of Lot 49*

This study was with and about youth who have high-functioning autism and their caregivers, and it was about sexuality. It was research about a sensitive topic with a vulnerable population. It was also an important topic with a unique population. It was research that went beyond quantitative form filling (though there was some of that as well), seeking deeper understanding through conversation. Because of such conversation, participants in this study

were able to share their perceptions and experiences in profound ways that may not have been accessible through other means. These participants shared candid information for the sake of research. In reviewing my research journal in search of meaning, one entry stands out as being particularly appropriate for the end of this journey:

As I reread the transcripts, now that some time has passed, it has become particularly obvious to me that I have much to learn in my leadership role in a program that is meant to provide personalized, family-centred services. Listening to these participants gives me pause to consider the ways in which I am responsible for creating or perpetuating unnecessary barriers to accessing our services. I now realize that research which was originally intended to be a “transformative” process for others was actually meant to be a personally transformative process. . . . I am meant to become an agent of positive change. (Journal entry, April 1, 2013)

It is my hope that we, who have been given the incredible job of making decisions about what is and is not important in the lives of these youth, listen. And after we listen, we do. Because in the end, the meaning is in the outcome.

## References

- Agthe-Diserens, C., & Valtré, F. (2001). *Du cœur au corps, formons-nous . . . puis formons –les. Programme de formation destiné aux professionnels en éducation et enseignement spécialisés, soignants et thérapeutes*. Nyon, Switzerland: Author.
- Albarracin, D., Gillette, J. C., Earl, A., Glasman, L. R., Duranti, M. R., & Ho, M. H. (2005). A test of the major assumptions about behavior change: A comprehensive look at the effects of passive and active HIV-prevention interventions since the beginning of the epidemic. *Psychological Bulletin*, *131*, 856–897. doi:10.1037/0033-2909.131.6.856
- Alberto, P. A., & Troutman, A. C. (2006). *Applied behavior analysis for teachers* (8th ed.). Upper Saddle River, NJ: Pearson Education.
- Allen, I. (1987). *Education in sex and personal relationships*. London, England: Policy Studies Institute.
- American Association on Intellectual and Developmental Disabilities. (2008). *Policies: The AAIDD definition of intellectual disability*. Retrieved March 24, 2013, from [http://www.aaidd.org/content\\_100.cfm](http://www.aaidd.org/content_100.cfm)
- American Association on Intellectual and Developmental Disabilities. (2013). *FAQ on intellectual disability*. Retrieved March 5, 2013, from [http://www.aaidd.org/content\\_104.cfm](http://www.aaidd.org/content_104.cfm)
- American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders*. Washington, DC: Author.
- American Psychiatric Association. (1968). *Diagnostic and statistical manual of mental disorders:DSV-II* (2nd ed.). Washington, DC: Author.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders:DSV-III* (3rd ed.). Washington, DC: Author.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders: DSV-III-TR* (3rd ed., text rev.). Washington, DC: Author.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders: DSM-IV* (4th ed.). Washington, DC: Author.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR* (4th ed., text rev.). Washington, DC: Author.
- American Psychiatric Association. (2012). *News release: DSM-5 proposed criteria for autism spectrum disorder designed to provide more accurate diagnosis and treatment*. Arlington, VA: Author. Retrieved March 5, 2013, from <http://www.dsm5.org/Documents/12-03%20Autism%20Spectrum%20Disorders%20-%20DSM5.pdf>

- American Psychiatric Association. (2013). *DSM-5 Autism spectrum disorder fact sheet*. Retrieved May 20, 2013 from <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-V* (5th ed.). Washington, DC: Author.
- Angera, J. J., Brookins-Fisher, J., & Inungu, J. N. (2008). An investigation of parent/child communication about sexuality. *American Journal of Sexuality Education, 3*, 165–181. doi:10.1080/15546120802104401
- Athanasiou, M. S., Geil, M., Hazel, C. E., & Copeland, E. P. (2002). A look inside school-based consultation: A qualitative study of the beliefs and practices of school psychologists and teachers. *School Psychology Quarterly, 17*, 258–298. doi:10.1521/scpq.17.3.258.20884
- Attwood, S. (2008). *Making sense of sex: A forthright guide to puberty, sex and relationships*. Philadelphia, PA: Jessica Kingsley.
- August, G. J., Anderson, D., & Bloomquist, M. L. (1992). Competence enhancement training: An integrated child, parent, and school approach. In S. L. Christenson & J. C. Conoley (Eds.), *Home-school collaboration: Enhancing children's academic and social competence* (pp. 175–192). Silver Springs, MD: National Association of School Psychologists.
- Autism Ontario. (2006). *Autism Ontario's response to special education transformation: The report of the co-chairs with the recommendations of the working table on special education*. Retrieved May 24, 2013, from [http://www.autismontario.com/Client/ASO/ao.nsf/object/Autism+Ontario+Special+Education+ransformation+Response/\\$file/Autism+Ontario+Special+Education+Transformation+Response.pdf](http://www.autismontario.com/Client/ASO/ao.nsf/object/Autism+Ontario+Special+Education+ransformation+Response/$file/Autism+Ontario+Special+Education+Transformation+Response.pdf)
- Autism Ontario. (2007). *Education policies*. Retrieved May 24, 2013, from [http://www.autismontario.com/Client/ASO/AO.nsf/object/Autism+Ontario+Education+Policies+2007/\\$file/Autism+Ontario+Education+Policies+2007.pdf](http://www.autismontario.com/Client/ASO/AO.nsf/object/Autism+Ontario+Education+Policies+2007/$file/Autism+Ontario+Education+Policies+2007.pdf)
- Avramidis, E., Bayliss, P., & Burden, R. (2000). Student teachers' attitudes towards the inclusion of children with special educational needs in the ordinary school. *Teaching and Teacher Education, 16*, 277–293. doi:10.1016/S0742-051X(99)00062-1
- Aylott, J. (2000). Autism in adulthood: The concepts of identity and difference. *British Journal of Nursing, 9*, 851–858.
- Bach, M. (2004). Competent/incompetent: Questioning the legal and social boundaries of personhood. *Dissertations Abstracts International, 65*(10), 422A. (UMI No. NQ94513)
- Bacharach, L. L. (1985). Deinstitutionalization: The meaning of the least restrictive environment. In R. H. Bruininks & K. C. Lakin (Eds.), *Living and learning in the least restrictive environment* (pp. 23–36). Baltimore, MD: Paul H. Brookes.

- Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *The Journal of Applied Behavior Analysis, 1*, 91–97. doi:10.1901/jaba.1968.1-91
- Baio, J. (2012). Prevalence of autism spectrum disorders—Autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Surveillance Summaries, 61* (SS03), 1–19. Retrieved March 3, 2013, from [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s\\_cid=ss6103a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w)
- Ballan, M. S. (2001). Parents as sexuality educators of their children with developmental disabilities. *SIECUS Report, 29*(3), 14–19.
- Ballan, M. S. (2012). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*, 676–684. doi:10.1007/s10803-011-1293-y
- Barnhill, G. P. (2007). Outcomes in adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 22*, 116–126. doi:10.1177/10883576070220020301
- Baron-Cohen, S. (2001). Theory of mind in normal development and autism. *Prisme, 34*, 174–183.
- Baron-Cohen, S., & Wheelwright, S. (2004). The empathy quotient: An investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. *Journal of Autism and Developmental Disabilities, 34*, 163–165. doi:10.1023/B:JADD.0000022607.19833.00
- Bennett, S., & Wynne, K. (May 2006). *Special education transformation: The report of the co-chairs with the recommendations of the working table on special education*. Toronto, ON: Queen's Printer for Ontario.
- Blakey, V., & Frankland, J. (1996). Sex education for parents. *Health Education, 5*, 9–13. doi:10.1108/09654289610125507
- Blanchett, W. J., & Wolfe, P. S. (2002). A review of sexuality education curricula Meeting the sexuality education needs of individuals with moderate and severe intellectual disabilities. *Research & Practice for Persons with Severe Disabilities, 27*, 43–57. doi:10.2511/rpsd.27.1.43
- Bloomberg, L. D., & Volpe, M. (2011). *Completing your qualitative dissertation: A roadmap from beginning to end* (2nd ed.). Thousand Oaks, CA: Sage.
- Boddington, P., & Podpadec, T. (1991). Who are the mentally handicapped? *Journal of Applied Philosophy, 8*, 177–190. doi:10.1111/j.1468-5930.1991.tb00280.x
- Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., . . . Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics, 127*, 1033–1042. doi:10.1542/peds.2010-2989

- Bricout, J. C., Porterfield, S., Tracey, C. M., & Howard, M. O. (2004). Linking models of disability for children with developmental disabilities. *Journal of Social Work in Disability and Rehabilitation*, 3(4), 45-66. doi:10.1300/J198v03n04\_04
- Bronfenbrenner, U. (1992). Ecological systems theory. In R. Vasta (ed.), *Six theories of child development: Revised formulations and current issues* (pp. 187–249). London, England: Jessica Kingsely.
- Brown, I. (2003). What do we mean by developmental disabilities in Ontario? In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (2nd ed., pp. 19–30). Toronto, Canada: Ontario Association on Developmental Disabilities.
- Bryson, S. E., Clark, B. S., & Smith, I. M. (1988). First report of a Canadian epidemiological study of autistic syndromes. *Journal of Child Psychology and Psychiatry*, 29, 433–446. doi:10.1111/j.1469-7610.1988.tb00735.x
- Cardinal, R. (1998). Teaching about sexuality in Grade 7–8 public school classrooms. *Masters Abstracts International*, 36(06), 1445. (UMI No. 738280811).
- CBC News. (2010, April 23). *Sex ed opponents claim victory in Ontario*. Retrieved from <http://www.cbc.ca/news/canada/toronto/story/2010/04/23/ontario-education.html>
- Centers for Disease Control and Prevention. (2010). *Autism Information Center: Facts about ASDs*. Retrieved March 24, 2013, from <http://www.cdc.gov/ncbddd/autism/facts.html>
- Chan, J., & John, R. M. (2012). Sexuality and sexual health in children and adolescents with autism. *The Journal for Nurse Practitioners*, 8, 306–315. doi:10.1016/j.nurpra.2012.01.020
- Children's Hospital of Eastern Ontario. (2013). *Autism intervention program: What is intensive behavioural intervention (IBI)?* Retrieved July 20, 2013, from <http://www.cheo.on.ca/en/ibi>
- Chin, H. Y., & Bernard-Opitz, V. (2000). Teaching conversation skills to children with autism: Effect on the development of theory of mind. *Journal of Autism and Developmental Disorders*, 30, 569–583. doi:10.1023/A:1005639427185
- Christensen, P., & James, A. (2000). Childhood diversity and commonality: Some methodological insights. In P. Christensen & A. James (Eds.), *Research with children: Perspectives and practices* (pp. 160–178). London, England: Falmer Press.
- Colton, D., & Colvert, R. W. (2007). *Designing and constructing instruments for social science research and evaluation*. San Francisco, CA: Wiley/Jossey-Bass.
- Community Living Ontario. (2013). *What is an intellectual disability*. Retrieved on March 5, 2013 from <http://www.communitylivingontario.ca/about-us/what-intellectual-disability>

- Connors, C., & Stalker, K. (2007). Children's experiences of disability: Pointers to a social model of childhood disability. *Disability & Society, 22*, 19–33. doi:10.1080/09687590601056162
- Constantine, N. A., Slater, J. K., & Carroll, J. (2007). Motivational aspects of community support for school-based comprehensive sexuality education. *Sex Education, 7*, 421–439. doi:10.1080/14681810701636002
- Cook, J. A. (2005). *“Patient-centred” and “consumer-directed” mental health services*. Chicago, IL: Institute of Medicine, Committee on Crossing the Quality Chasm—Adaptation to Mental Health and Addictive Disorders.
- Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2nd ed.). Upper Saddle River, NJ: Prentice-Hall.
- Craft, A. (Ed.). (1994). *Practice issues in sexuality and learning disabilities*. London, England: Routledge.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage.
- Creswell, J. , & Miller, D. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39*, 124–130. doi:10.1207/s15430421tip3903\_2
- Creswell, J. W., & Plano Clark, V. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: Sage.
- Davies, C., & Dubie, M. (2012). *Intimate relationships and sexual health: A curriculum for teaching adolescents/adults with high-functioning autism spectrum disorders and other social challenges*. Shawnee Mission, KS: Autism Asperger.
- Demetral, D. G. (1981). Does ignorance really produce irresponsible behavior? *Sexuality and Disability, 4*, 151–160. doi:10.1007/BF01277432
- DeVellis, R. F. (2003). *Scale development: Theory and application*. Thousand Oaks, CA: Sage.
- Di Giulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *The Canadian Journal of Human Sexuality, 12*, 53–68.
- Donovan, P. (1998). School-based sexuality education: The issues and challenges. *Family Planning Perspectives, 30*, 188–193. doi:10.2307/2991682
- Duquette, C. A., Fullarton, S., Orders, S., & Robertson-Grewal, K. (2011). Insider, outsider, ally, or adversary: Parents of youth with learning disabilities engage in educational advocacy. *International Journal of Special Education, 26*(3), 124–141.

- Durocher, L., Fortier, M. (1999). *Programme d'éducation sexuelle*. Montréal, QC: Les Centres Jeunesse de Montréal et la Régie régionale de la santé et des services sociaux, Direction de la santé publique.
- Eldar, E., Talmor, R., & Wolf-Zukerman, T. (2010). Successes and difficulties in the individual inclusion of children with Autism Spectrum Disorder (ASD) in the eyes of their coordinators. *International Journal of Inclusive Education*, *14*, 97–114. doi:10.1080/13603110802504150
- Fernandez, C. (2008; Reaffirmed January 30, 2013). Position statement: Ethical issues in health research in children. *Paediatrics & Child Health*, *13*, 707–712. Retrieved May 15, 2013, from <http://www.pulsus.com/journals/abstract.jsp?sCurrPg=abstract&jnlKy=5&atlKy=8350&isuKy=813&isArt=t&fromfold=Past+Issues%2CTable+Of+Contents&fold=Abstract>
- Fielding, M. (2004). Transformative approaches to student voice: Theoretical underpinnings, recalcitrant realities. *British Educational Research Journal*, *30*, 295–311. doi:10.2307/1502226
- Fombonne, E., Zakarian, R., Bennett, A., Meng, L., & McLean-Haywood, D. (2006). Pervasive developmental disorders in Montréal, Québec, Canada: Prevalence and links with immunizations. *Pediatrics*, *118*, 139–150. doi:10.1542/peds.2005-2993
- Fraenkel, J. R., & Wallen, N. E. (2003). *How to design and evaluate research in education*. San Francisco, CA: McGraw-Hill.
- Frith, U. (1989). *Autism: Explaining the enigma*. Oxford, England: Blackwell.
- Fuchs, D., & Fuchs, L. S. (1994). Inclusive schools movement and the radicalization of special education reform. *Exceptional Children*, *60*, 294–309.
- Gagnon, Y.-C. (2005). *L'étude de cas comme méthode de recherche*. Sainte-Foy, Canada: Presse de l'Université du Québec.
- Galluci, G., Hackerman, F., & Schmidt, C. W. (2005). Gender identity disorder in an adult male with Asperger's syndrome. *Sexuality and Disability*, *23*, 35–40. doi:10.1007/s11195-004-2078-4
- Gardner, J. F., & Chapman, M. S. (1990). *Program issues in developmental disabilities: A guide to effective habilitation and active treatment* (2nd ed.). Baltimore, MD: Paul H. Brookes.
- Gartner, A., & Lipsky, D. K. (1987). Beyond special education: Toward a quality system for all students. *Harvard Educational Review*, *57*, 367–395.
- Gearing, R. (2004). Bracketing in research: A typology. *Qualitative Health Research*, *14*, 1429–1452. doi:10.1177/1049732304270394

- George, D., & Mallery, P. (2003). *SPSS for Windows step by step: A simple guide and reference. 11.0 update* (4th ed.). Boston, MA: Allyn & Bacon.
- Gerhardt, P. F. (2006, November/December). Sexuality instruction and autism spectrum disorders. *Autism Asperger's Digest*, 44–46. Retrieved from <http://autismdigest.com/sexuality-instruction-and-asds/>
- Gerouki, M. (2007). Sexuality and relationships education in the Greek primary schools—See no evil, hear no evil, speak no evil. *Sex Education*, 7, 81–100. doi:10.1080/14681810601134710
- Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (Eds.). (1993). *Through the patient's eyes: Understanding and promoting patient-centered care*. San Francisco, CA: Jossey-Bass.
- Geschwind, D. H. (2009). Advances in autism. *Annual Review of Medicine*, 60, 367–380. doi:10.1146/annurev.med.60.053107.121225.
- Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in persons with autism: Implications for research and clinical care. *Journal of Autism and Developmental Disorders*, 32, 299–305. doi:10.1023/A:1016330802348
- Gilmour, L., Schalomon, P. M., & Smith, V. (2012). Sexuality in a community based sample of adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 6, 313–318. doi:10.1016/j.rasd.2011.06.003
- Goode, S., Howlin, P., & Rutter, M. (1999). *A cognitive and behavioural study of outcome in youth adults with autism* (Unpublished data).
- Gordon, S. (1971). Missing in special education: Sex. *The Journal of Special Education*, 5, 351–354. doi:10.1177/002246697100500406
- Gougeon, N. A. (2009). Sexuality education for students with intellectual disabilities, A critical pedagogical approach: Outing the ignored curriculum. *Sex Education*, 3, 277–291. doi:10.1080/14681810903059094
- Gougeon, N. A. (2010). Sexuality and autism: A critical review of selected literature using a social-relational model of disability. *The American Journal of Sexuality Education*, 5, 328–361. doi:10.1080/15546128.2010.527237
- Gougeon, N. A. (2011). *Personalized service: Practical and theoretical considerations. Strategic Research Fund Report submitted to the Ontario Ministry of Children and Youth Services* (Unpublished document).
- Gougeon, N. A., & Sénéchal, C. (2010). Addressing the achievement gap for students with autism through the development of socially inclusive curriculum. *Journal of the International Association for the Study of the Global Achievement Gap*, 1, 11–17.

- Gray, S., Ruble, L., & Dalrymple, N. (2000). *Autism and sexuality: A guide for instruction*. Bloomington, IN: Autism Society of Indiana.
- Greenspan, S. (2002). A sex police for adults with “Mental Retardation”? Comment on Spiecker and Steutel. *Journal of Moral Education*, 31, 171–179. doi:10.1080/03057240220143278
- Gresham, F., & Lopez, M. (1996). Social validation: A unifying concept for school-based consultation research and practice. *School Psychology Quarterly*, 11, 204–227. doi:10.1037/h0088930
- Griffin-Shelley, E. (2010). An Asperger’s adolescent sex addict, sex offender: A case study. *Sexual Addiction & Compulsivity*, 17, 46–64. doi:10.1080/10720161003646450
- Griffiths, D. (2003). Sexuality and people who have developmental disabilities: From myth to emerging practices. In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (2nd ed., pp. 677–690). Toronto, Canada: Ontario Association on Developmental Disabilities.
- Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. Philadelphia, PA: Basic Books.
- Guba, E. G., & Lincoln, Y. S. (1998). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln. (Eds.), *Handbook of qualitative research* (pp. 105–117). Thousand Oaks, CA: Sage.
- Gulick, R. F., & Kitchen, T. P. (2007). *Effective instruction for children with autism*. Erie, PA: The Gertrude A. Barber National Institute.
- Hall, S. A. (2009). The social inclusion of people with disabilities: A qualitative meta-analysis. *Journal of Ethnographic & Qualitative Research*, 3, 162–173.
- Halstead, J. M., & Reiss, M. J. (2003). *Values in sex education: From principles to practice*. London, England: Routledge-Farmer.
- Happé, F. (1999). Understanding assets and deficits in autism: Why success is more interesting than failure. *Psychologist*, 12, 540–547.
- Hatton, S., & Tector, A. (2010). Sexuality and relationship education for young people with autistic spectrum disorder: Curriculum change and staff support. *British Journal of Special Education*, 37, 69–76. doi:10.1111/j.1467-8578.2010.00466.x
- Hegarty, S. (1985). Qualitative research: Introduction. In S. Hegarty & P. Evans (Eds.), *Research and evaluation methods in special education* (pp. 1–14). Windsor, England: National Foundation for Educational Research–Nelson.

- Hellemans, H., Colson, K., Verbraeken, C., Vermeiren, R., & Deboutte, D. (2007). Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *37*, 260–269. doi:10.1007/s10803-006-0159-1
- Hénault, I. (2005). Sexuality and Asperger syndrome: The need for socio-sexual education. In K. P. Stoddart (Ed.), *Children, youth and adults with Asperger syndrome: Integrating multiple perspectives* (pp. 110–124). Philadelphia, PA: Jessica Kingsley.
- Hénault, I. (2006). *Asperger's syndrome and sexuality*. Philadelphia, PA: Jessica Kingsley.
- Hénault, I., & Attwood, T. (2002, November). *The sexual profile of adults with Asperger's syndrome: The need for understanding, support, and sex education*. Paper presented at the Inaugural World Autism Congress, Melbourne Australia.
- Hénault, I., Forget, J., & Giroux, N. (2003). *Le développement d'habiletés sexuelles adaptives chez des individus atteints d'autisme de haut niveau ou du syndrome d'Asperger* (Unpublished doctoral dissertation). Université du Québec à Montréal.
- Herold, E. S., & Benson, R. M. (1979). Problems of teaching sex education—A survey of Ontario secondary schools. *The Family Coordinator*, *28*, 199–203.
- Herr, S., Gostin, L., & Hongju Koh, H. (Eds.). (2003). *The human rights of persons with intellectual disabilities: Different but equal*. New York, NY: Oxford University.
- Hingsburger, D., Griffiths, D., & Quinsey, V. (1991). Detecting counterfeit deviance. *The Habilitative Mental Healthcare Newsletter*, *10*(9), 51–54.
- Hingsburger, D., & Tough, S. (2002). Healthy sexuality: Attitudes, systems, and policies. *Research and Practice for Persons with Severe Disabilities*, *27*, 8–17. doi:10.2511/rpsd.27.1.8
- Hoagwood, K., Burns, B. J., Kiser, L., Ringeisen, H., & Schoenwald, S. K. (2001). Evidence-based practice in child and adolescent mental health services. *Psychiatric Services*, *52*, 1179–1190. doi:10.1176/appi.ps.52.9.1179
- Holburn, S., Jacobson, J. W., Vietze, P. M., Schwartz, A. A., & Serson, E. (2000). Quantifying the process and outcomes of person-centered planning. *American Journal on Mental Retardation*, *105*, 402–416.
- Horne, P. E., & Timmons, V. (2009). Making it work: Teachers' perspectives on inclusion. *International Journal of Inclusive Education*, *13*, 273–286. doi:10.1080/13603110701433964
- Horrocks, J. L., White, G., & Roberts, L. (2008). Principals' attitudes regarding inclusion of children with autism in Pennsylvania public schools. *Journal of Autism and Developmental Disorders*, *38*, 1462–1473. doi:10.1007/s10803-007-0522-x

- Howard, E. M. (2001). Exceptional students and sexuality education: Teachers' beliefs, professional preparation, and practices. *Dissertation Abstracts International*, 62(10), 3345A. (UMI No. 3027528)
- Howard-Barr, E. M., Rienzo, B. A., Pigg, R. M., Jr., & James, D. (2005). Teacher beliefs, professional preparation, and practices regarding exceptional students and sexuality education. *Journal of School Health*, 75, 99–104. doi:10.1111/j.1746-561.2005.tb06649.x
- Howlin, P. (2000). Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism*, 4, 63–83. doi:10.1177/1362361300004001005
- Howlin, P. (2004). *Autism and Asperger syndrome: Preparing for adulthood* (2nd ed.). New York, NY: Routledge.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45, 212–229. doi:10.1111/j.1469-7610.2004.00215.x
- Howlin, P., Mawhood, L. M., & Rutter, M. (2000). Autism and developmental receptive language disorder: A follow-up comparison in early adult life: II. Social, behavioural and psychiatric outcomes. *Journal of Child Psychology and Psychiatry*, 41, 561–578. doi:10.1111/1469-7610.00643
- Hutchfield, K. (1999). Family-centered care: A concept analysis. *Journal of Advanced Nursing*, 29, 1178–1187. doi:10.1046/j.1365-2648.1999.00987.x
- International Planned Parenthood Federation. (2012). *Sexual rights: An IPPF declaration*. Retrieved July 15, 2013, from <http://ippf.org/resource/Sexual-Rights-IPPF-declaration>
- Jasmin, E., Couture, M., McKinley, P., Reid, G., Fombonne, E., & Gisel, E. (2009). Sensori-motor and daily living skills of preschool children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 39, 231–241. doi:10.1007/s10803-008-0617-z
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7), 14–26. doi:10.3102/0013189X033007014
- Kaesler, F. (1992). Can people with severe mental retardation consent to mutual sex? *Sexuality and Disability*, 10, 33–42. doi:10.1007/BF01102246
- Kalyva, E. (2010). Teachers' perspectives of the sexuality of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 4, 433–437. doi:10.1016/j.rasd.2009.10.014
- Kanner, L. (1943). Autistic disturbances of affective contact. *The Nervous Child*, 2, 217–250.

- Kempton, W. (1993). *Socialization and sexuality: A comprehensive guide*. Santa Barbara, CA: James Stanfield.
- Kirby, D. (2000). What does the research say about sexuality education? *Educational Leadership*, 58(2), 72–77.
- Kirby, D., Laris, B. A., & Rolleri, L. (2007). Sex and HIV education programs: Their impact on sexual behaviors of young people throughout the world. *Journal of Adolescent Health*, 40, 206–217. doi:10.1016/j.jadohealth.2006.11.143
- Kline, P. (1999). *The handbook of psychological testing* (2nd ed.). London, England: Routledge.
- Koegel, L. K., & LaZebnik, C. (2009). *Growing up on the spectrum: A guide to life, love, and learning for teens and young adults with autism and Asperger's*. New York, NY: Viking.
- Koller, R. (2000). Sexuality and adolescents with autism. *Sexuality and Disability*, 18, 125–135.
- Konstantareas, M. M., & Lunsby, Y. (1997). Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay. *Journal of Autism and Developmental Disorders*, 27, 397–413. doi:10.1023/A:1025805405188
- Koughan, F. (2013). Raising Adam Lanza. In J. Beshenkovsky & F. Koughan (Prods.). *Frontline*. PBS. Retrieved May 27, 2013, from <http://www.pbs.org/wgbh/pages/frontline/social-issues/raising-adam-lanza/transcript-39/>
- Kreinin, T. (2001). Sexuality education for the disabled is priority at home and school. *SIECUS Report*, 29(3), 3.
- La Malfa, G., Lassi, S., Bertelli, M., Salvini, R., & Placidi, G. F. (2004). Autism and intellectual disability: A study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research*, 48, 262–267. doi:10.1111/j.1365-2788.2003.00567.x
- Laidlaw Foundation. (2002). *Ethical reflections on social inclusion* (Working Papers Series—Perspectives on Social Inclusion). Toronto, ON: Author.
- Lamb, S., Lustig, K., & Graling, K. (2013). The use and misuse of pleasure in sex education curricula. *Sex Education*, 13, 305–318. doi:10.1080/14681811.2012.738604
- Lavoie, R. (2005). *It's so much work to be your friend: Helping the child with learning disabilities find social success*. New York, NY: Simon & Schuster.
- Lawson, W. (2005). *Sex, sexuality and the Autism spectrum*. Philadelphia, PA: Jessica Kingsley.
- Leicester, M., & Cooke, P. (2002). Rights not restrictions for learning disabled adults: A response to Spiecker and Steutel. *Journal of Moral Education*, 31, 181–187. doi:10.1080/03057240220143287

- Lester, J. N. (2011). *The discursive construction of autism: Contingent meanings of autism and therapeutic talk* (Doctoral dissertation). Retrieved from [http://trace.tennessee.edu/utk\\_graddiss/990/](http://trace.tennessee.edu/utk_graddiss/990/)
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lindner, J. L., & Rosén, L. A. (2006). Decoding of emotion through facial expression, prosody and verbal content in children and adolescents with Asperger's syndrome. *Journal of Autism and Developmental Disorders*, *36*, 769–777. doi:10.1007/s10803-006-0105-2
- Love, B. (2004). United States: Significant unconventional sexual behaviors. D: Paraphilias and unusual sexual practices. In R. T. Francoeur & R. J. Noonan (Eds.), *The Continuum complete international encyclopedia of sexuality* (pp. 1245–1250). New York, NY: Continuum.
- Lyden, M. (2007). Assessment of sexual consent capacity. *Sexuality and Disability*, *25*, 3–20. doi:10.1007/s11195-006-9028-2
- Lyons, J. S. (2009a). *Communimetrics: A communication theory of measurement in human service settings*. New York, NY: Springer.
- Lyons, J. S. (2009b). Knowledge creation through total clinical outcomes management: A practice-based evidence solution to address some of the challenges of knowledge translation. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, *18*, 38–45.
- Mansell, S., Sobsey, D., & Moskal, R. (1998). Clinical findings among sexually abused children with and without developmental disabilities. *Mental Retardation*, *36*, 12–22. doi:10.1352/0047-6765(1998)036<0012:CFASAC>2.0.CO;2
- Marriage, S., Wolverton, A., & Marriage, K. (2009). Autism spectrum disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, *18*, 322–328.
- Marshall, C., & Rossman, G. B. (2011). *Designing qualitative research* (5th ed.). Thousand Oaks, CA: Sage.
- Marsman, J. C., & Herold, E. S. (1986). Attitudes toward sex education and values in sex education. *Family Relations*, *35*, 357–361. doi:10.2307/584361
- Mauthner, M. (1997). Methodological aspects of collecting data from children: Lessons from three research projects. *Children and Society*, *11*, 16–28. doi:10.1002/(SICI)1099-0860(199704)11:1<16::AID-CHI54>3.0.CO;2-D
- Mawhood, L. M., Howlin, P., & Rutter, M. (2000). Autism and developmental receptive language disorder: A follow-up comparison in early adult life: I. Cognitive and language outcomes. *Journal of Child Psychology and Psychiatry*, *41*, 547–559. doi:10.1111/1469-7610.00642

- McCabe, M. P. (1993). Sex education programs for people with mental retardation. *Mental Retardation*, 31, 377–387. doi:10.1352/0046765(1998)036<0012:CFASAC>2.0.CO;2
- McKay, A., & Bissell, M. (2010). *Sexuality Information and Education Council of Canada (SIECCAN) Sexual health education in the schools: Questions and answers* (3rd ed.). Toronto, ON: Sexuality Information and Education Council of Canada.
- McKay, A., Pietrusiak, M.-A., & Holowaty, P. (1998). Parents' opinions and attitudes towards sexuality education in the schools. *The Canadian Journal of Human Sexuality*, 7, 139–145.
- Mehzabin, P., & Stokes, M. A. (2011). Self-assessed sexuality in young adults with high-functioning autism. *Research in Autism Spectrum Disorders*, 5, 614–621. doi:10.1016/j.rasd.2010.07.006
- Meister, C., Norlock, D., Honeyman, S., & Pierce, K. (1994). Sexuality and autism: A parenting skills enhancement group. *Canadian Journal of Human Sexuality*, 3, 283–289.
- Merriam, S. (1988). *Case study in education: A qualitative approach*. San-Francisco, CA: Jossey-Bass.
- Mertens, D. M. (2007). Transformative paradigm: Mixed methods and social justice. *Journal of Mixed Methods Research*, 1, 212–225. doi:10.1177/1558689807302811
- Mertens, D. M., & McLaughlin, J. A. (2004). *Research and evaluation methods in special education*. Thousand Oaks, CA: Sage.
- Middletown Centre for Autism. (n.d.). *Autism spectrum disorder: Relationships and sexuality*. (Research Bulletin Issue No. 5). Middletown, Northern Ireland: Author.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.
- Mitchell, L. (2010, August). *Bringing the birds & bees down to earth: Sexuality education for individuals with autism*. Paper presented at the 2010 Penn State National Autism Conference. Retrieved March 24, 2013, from <http://www.outreach.psu.edu/programs/autism/files/48mitchell.pdf>
- Mitchell, P., & O'Keefe, K. (2008). Brief report: Do individuals with autism spectrum disorder think they know their own minds? *Journal of Autism and Developmental Disorders*, 38, 1591–1597. doi:10.1007/s10803-007-0530-x
- Monat-Haller, R. K. (1992). *Understanding & expressing sexuality: Responsible choices for individuals with developmental disabilities*. Baltimore, MD: Paul H. Brookes.
- Montalbano, R., & Roccella, M. (2009). The quality of life of children with pervasive developmental disorders. *Minerva Pediatrics*, 61, 361–370.

- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Murphy, N. A., & Roy Elias, E. (2006). Sexuality of children and adolescents with developmental disabilities. *Pediatrics*, *118*, 398–403. doi:10.1542/peds.2006-1115
- National Autistic Society. (2011). *How to talk about autism*. Retrieved July 15, 2013, from <http://www.autism.org.uk/news-and-events/media-centre/how-to-talk-about-autism.aspx>
- National Foundation for Educational Research. (1995). *Parents, schools and sex education: A compelling case for partnership*. London, England: Health Education Authority.
- Nichols, S. (2005). *Parenting and sexuality scale*© (Unpublished tool).
- Nichols, S. (2005). *Youth sexuality development scale*© (Unpublished tool).
- Nichols, S., & Blakeley-Smith, A. (2009). “I’m not sure we’re ready for this. . .”: Working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders. *Social Work in Mental Health*, *8*, 72–91. doi:10.1080/15332980902932383
- Nichols, S., Moravcik, G. M., & Pulver Tetenbaum, S. (2009). *Girls growing up on the autism spectrum: What parents and professionals should know about the pre-teen and teenage years*. Philadelphia, PA: Jessica Kingsley.
- Niederbuhl, J. M., & Morris, C. D. (1993). Sexual knowledge and the capability of persons with dual diagnoses to consent to sexual contact. *Sexuality and Disability*, *11*, 295–307. doi:10.1007/BF01102174
- Norwich, B. (2002). Education, inclusion and individual differences: Recognising and resolving dilemmas. *British Journal of Educational Studies*, *50*, 482–502. doi:10.1111/1467-8527.t01-1-00215
- Nunnally J. C., & Bernstein, I. H. (1994). *Psychometric theory* (3rd ed.). New York, NY: McGraw-Hill.
- Nussbaum, M. C. (2006). *The frontiers of justice*. Cambridge, MA: The Belknap Press.
- Olley, J. G. (1999). Curriculum for students with autism. *School Psychology Review*, *28*, 595–607.
- Ontario Ministry of Children and Youth Services. (2010). *Strategic framework 2008–2012: Strategic goals*. Retrieved June 1, 2013, from <http://www.children.gov.on.ca/htdocs/English/about/strategicframework/strategicgoals.aspx>
- Ontario Ministry of Children and Youth Services. (2011a, April). *Ontario’s strategy for children and youth with autism spectrum disorders presentation*. Paper presented to Child Psychiatry Day, Ministry of Children and Youth Services, Toronto, Canada.

- Ontario Ministry of Children and Youth Services. (2011b). *Programs and services for children and youth with autism*. Retrieved June 5, 2013, from <http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/autism/programs.aspx>
- Ontario Ministry of Community and Social Services. (2008). *Services and supports to promote the social inclusion of persons with developmental disabilities Act, 2008, S.O. 2008, c. 14 - Bill 77*. Retrieved June 1, 2013 from [http://www.e-laws.gov.on.ca/html/statutes/english/elaws\\_statutes\\_08s14\\_e.htm](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_08s14_e.htm)
- Ontario Ministry of Education (MEDU). (1998/2005). *The Ontario curriculum, Grades 1–8: Health and physical education*. Retrieved June 1, 2013, from <http://www.edu.gov.on.ca/eng/curriculum/elementary/health18curr.pdf>
- Ontario Ministry of Education. (1999). *The Ontario curriculum, Grades 9 and 10: Health and physical education*. Toronto, ON: Queen’s Printer for Ontario.
- Ontario Ministry of Education. (2000). *The Ontario curriculum, Grades 11 and 12: Health and physical education*. Toronto, ON: Queen’s Printer for Ontario.
- Ontario Ministry of Education. (2001). *Special education: A guide for educators*. Retrieved July 15, 2013, from <http://www.edu.gov.on.ca/eng/general/elemsec/speced/guide/specedhandbooke.pdf>
- Ontario Ministry of Education. (2004). *The individual education plan (IEP): A resource guide*. Toronto, ON: Queen’s Printer for Ontario.
- Ontario Ministry of Education. (2007). *Policy/program memorandum 140*. Retrieved May 23, 2013, from <http://www.edu.gov.on.ca/extra/eng/ppm/140.pdf>
- Ontario Ministry of Education. (2009). *Ontario’s equity and inclusive education strategy: Realizing the promise of diversity*. Toronto, ON: Queen’s Printer for Ontario.
- Ontario Ministry of Education. (2010a). *The Ontario curriculum, Grades 1 to 8: Health and physical education*. Toronto, ON: Author. Retrieved March 9, 2013, from <http://www.peopleforeducation.ca/document/ontario-health-and-physical-education-elementary-full-2010-edition/76/>
- Ontario Ministry of Education. (2010b). *The Ontario curriculum, Grades 1 to 8: Health and physical education (Interim ed.)*. Toronto, ON: Queen’s Printer for Ontario. Retrieved March 9, 2013, from <http://www.edu.gov.on.ca/eng/curriculum/elementary/healthcurr18.pdf>
- Open Future Learning. (2012). *Sexuality and relationships module*. Retrieved May 15, 2013, from <http://www.openfuturelearning.org/learningmodules.html#Relationships>
- Ophea. (2010). *Ontario students need a quality health and physical education curriculum*. Retrieved March 24, 2013 from <http://www.ophea.net/about-us/quality-hpe-curriculum>

- Ousley, O. Y., & Mesibov, G. B. (1991). Sexual attitudes and knowledge of high-functioning adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, *21*, 471–481. doi:10.1007/BF02206871
- Ozonoff, S., South, M., & Miller, J. N. (2000). DSM-IV-defined Asperger syndrome: Cognitive, behavioral, and early history differentiation from high-functioning autism. *Autism*, *4*, 29–46. doi:10.1177/1362361300041003
- Palmer, M. (2012). Sext up kids. In R. LeGuerrier & T. M. Hogan (Prods.). *Doc Zone*. CBC.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Pearson, M. (2013, January 31). Update health, sex-ed curriculum, groups urge Kathleen Wynne. *The Ottawa Citizen*. Retrieved from <http://www.ottawacitizen.com/life/Update+health+curriculum+groups+urge+Kathleen+Wynne/7901101/story.html>
- Peck, C. A., & Furman, G. C. (1992). Qualitative research in special education: An evaluative review. In R. Gaylord-Ross (Ed.), *Issues and research in special education*, Vol. 2. (pp. 1–42). New York, NY: Teachers College Press.
- Perrin, J. M., Romm, D., Bloom, S. R., Homer, C. J., Kulthau, K. A., Cooley, C., . . . Newacheck, P. (2007). A family-centered, community-based system of services for children and youth with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, *161*, 933–936. doi:10.1001/archpedi.161.10.933
- Peters, J. E. (2007). An exploration of the attitudes and perspectives of special education teachers towards the teaching of human sexuality education. *Dissertation Abstracts International*, *68*(03), 117A. (UMI No. 3255136)
- Plaute, W., Westling, D., & Cizek, B. (2002). Sexuality education for adults with cognitive disabilities in Austria: Surveys of attitudes and the development of a model program. *Research and Practice for Persons with Severe Disabilities*, *27*, 58–68. doi:10.2511/rpsd.27.1.58
- Praisner, C. L. (2003). Attitudes of elementary school principals toward the inclusion of students with disabilities. *Exceptional Children*, *69*, 135–145.
- Public Health Agency of Canada. (2008). *Canadian guidelines for sexual health education*. Toronto, CA: Author.
- Pynchon, T. (1990). *The crying of lot 49*. New York, NY: Harper & Row. (Original work published 1966)
- QSR International. (2010). NVivo (version 9) [Qualitative data analysis software]. Victoria, Australia: QSR International.

- Radford, J. P., & Park, D. C. (2003). Historical overview of developmental disabilities in Ontario. In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (2nd ed., pp. 3–18). Toronto, ON: Ontario Association on Developmental Disabilities.
- Rawana, J., Norwood, S., & Whitley, J. (2011). A mixed-method evaluation of a strength-based bullying prevention program. *Canadian Journal of School Psychology, 26*(4), 1–18. doi:10.1177/0829573511423741
- Realmuto, G. M., & Ruble, L. A. (1999). Sexual behaviors in autism: Problems of definition and management. *Journal of Autism and Developmental Disorders, 29*, 121–127. doi:10.1023/A:1023088526314
- Rebeiro, K. L. (2000). Client perspectives on occupational therapy practice: Are we truly client-centred? *Canadian Journal of Occupational Therapy, 67*, 7–14. doi:10.1177/000841740006700103
- Reindal, S. M. (2008). A social-relational model of disability: A theoretical framework for special needs education? *European Journal of Special Needs Education, 23*, 135–146. doi:10.1080/08856250801947812
- Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism, 10*, 511–524. doi:10.1177/1362361306066604
- Rodgers, B. (1993). Concept analysis: An evolutionary view. In B. Rodgers & K. Knafel (Eds.), *Concept development in nursing* (pp. 73–92). Philadelphia, PA: W. B. Saunders.
- Rogers, C. (2007). Experiencing an “inclusive” education: Parents and their children with special educational needs. *British Journal of Sociology of Education, 28*, 55–68. doi:10.1080/01425690600996659
- Rogers, S. J. (2000). Interventions that facilitate socialization in children with Autism. *Journal of Autism and Developmental Disorders, 30*, 399–409. doi:10.1023/A:1005543321840
- Ronald, A., & Hoekstra, R. A. (2011). Autism spectrum disorders and autistic traits: A decade of new twin studies. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics, 156*, 255–274. doi:10.1002/ajmg.b.31159
- Roth, M. E. (2009). Puberty and relationships 101: A guide to growing up for high functioning adolescent males with Autism Spectrum Disorders. *Masters Abstracts International, 48*(01). (UMI No. 1468873)
- Ruble, L. A., & Dalrymple, N. J. (1993). Social/sexual awareness of persons with autism: A parental perspective. *Archives of Sexual Behavior, 22*, 229–240. doi:10.1007/BF01541768

- Ruble, L. A., & Dalrymple, N. J. (2002). COMPASS: A parent-teacher collaborative model for students with autism. *Focus on Autism and Other Developmental Disabilities, 17*, 76–83. doi:10.1177/10883576020170020201
- Ruble, L. A., Dalrymple, N. J., & McGrew, J. H. (2010). The effects of consultation on the individualized education program outcomes for young children with autism: The collaborative model for promoting competence and success. *The Journal of Early Intervention, 32*, 286–301. doi:10.1177/1053815110382973
- Ruble, L. A., Dalrymple, N. J., & McGrew, J. H. (2012). *COMPASS: Providing direction—A collaborative model for promoting competence and success for persons with an autism spectrum disorder*. New York, NY: Springer.
- Ruble, L. A., & Mathai, G. (2010). COMPASS: Finding direction for individuals with autism spectrum disorders. *International Public Health Journal, 2*(1S), 51–66.
- Ruble, L., & Sears, L. (2000). Diagnostic assessment of autistic disorder. In R. Huebner (Ed.), *Sensory approach to management of autistic and related disorders* (pp. 41–59). Frederick, MD: Aspen.
- Sameroff, A. J., & Fiese, B. H. (1990). Transactional regulation and early intervention. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early intervention* (pp. 119–149). New York, NY: Cambridge University Press.
- Schalock, R. L., Luckasson, R. A., Shogren, K. A., Borthwick-Duffy, S., Bradley, V., Buntinx, W. H. E., . . . Yeager, M. H. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities, 45*, 116–124. doi:10.1352/1934-9556(2007)45[116:TROMRU]2.0.CO;2
- Schwartz-Barcott, D., & Kim, S.K. (1993). An expansion and elaboration of the hybrid model of concept development in nursing. In B. Rodgers & K Knafl (Eds), *Concept development in nursing* (pp. 107–133). Philadelphia, PA: W. B. Saunders.
- Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (3rd ed.). New York, NY: Teachers College Press.
- Sexuality Information and Education Council of the United States. (2001). Position statement. *SIECUS Report, 29*(3), 2.
- Sexuality Information and Education Council of the United States, National Guidelines Task Force. (2004). *Guidelines for comprehensive sexuality education* (3rd ed.). New York, NY: Fulton Press.
- Shakespeare, T., Gillespie-Sells, K. & Davies, D. (1996). *The sexual politics of disability, untold desires*. London, England: Cassell.
- Shelton T. L. & Smith Stepanek, J. (1995). Excerpts from family-centered care for children needing specialized health and developmental services. *Pediatric Nursing, 21*, 362–364.

- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*, 63–75.
- Sieswerda, L. E., & Blekkenhorst, P. (2003). *Parental attitudes towards sex education in the home*. Thunder Bay, ON: Thunder Bay District Health Unit.
- Simpson, R. (2001). ABA and students with autism spectrum disorders: Issues and considerations for effective practice. *Focus on Autism and Other Developmental Disabilities, 16*, 68–71. doi:10.1177/108835760101600202
- Smith Myles, B., & Simpson, R. L. (2001). Understanding the hidden curriculum: An essential social skill for children and youth with Asperger syndrome. *Intervention in School and Clinic, 36*, 279–286. doi:10.1177/105345120103600504
- Sobsey, D. (1994). *Violence and abuse in the lives of persons with disabilities: The end of silent acceptance?* Baltimore, MD: Paul H. Brookes.
- Somers, C. L., & Paulson, S. E. (2000). Students' perceptions of parent-adolescent closeness and communication about sexuality: Relations with sexual knowledge, attitudes, and behaviors. *Journal of Adolescence, 23*, 629–644. doi:10.1006/jado.2000.0349
- Spriggs, M., Gillam, L., Thomson, C., & Oakley, J. (2010). *Understanding consent in research involving children: The ethical issues—A handbook for human research ethics committees and researchers*. Melbourne, Australia: The Royal Children's Hospital Melbourne. Retrieved March 5, 2013, from <http://www.mcri.edu.au/media/62539/handbook.pdf>
- Stainback, S., & Stainback, W. (1992). *Curriculum considerations in inclusive classrooms: Facilitating learning for all students*. Baltimore, MD: Paul H. Brookes.
- Stake, R. E. (1995). *The art of case study research*. Thousand Oaks, CA: Sage.
- Stavis, P. F. (1991). Harmonizing the right to sexual expression and the right to protection from harm for persons with mental disability. *Sexuality and Disability, 9*, 131–141. doi:10.1007/BF01101738
- Steutel, J., & Spiecker, B. (2004). Sex education, state policy and the principle of mutual consent. *Sex Education, 4*, 49–62. doi:10.1080/1468181042000176533
- Stokes, M. A., Kaur, A. (2005). High-functioning autism and sexuality: A parental perspective. *Autism, 9*, 266–289. doi:10.1177/1362361305053258
- Stokes, M. A., Newton, N., & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 37*, 1969–1986. doi:10.1007/s10803-006-0344-2

- Stone, N., & Ingham, R. (1998). Exploration of the factors that affect the delivery of sex and sexuality education and support in schools: *Final report*. University of Southampton, UK: Centre for Sexual Health Research.
- Stroul, B. A. (1993). *Systems of care for children and adolescents with severe emotional disturbances: What are the results?* Washington, DC: Georgetown University Child Development Center.
- Sullivan, A., & Caterino, L. C. (2008). Addressing the sexuality and sex education of individuals with Autism Spectrum Disorder. *Education & Treatment of Children, 31*, 381–394. doi: 10.1353/etc.0.0001
- Swain, J., French, S., & Cameron, C. (2003). *Controversial issues in a disabling society*. Philadelphia, PA: Open University Press.
- Szatmari, P., Bartolucci, G., Bremner, R. S., Bond, S., & Rich, S. (1989). A follow-up study of high functioning autistic children. *Journal of Autism and Developmental Disorders, 19*, 213–226. doi:10.1007/BF02211842
- Tantam, D. (1991). Asperger's syndrome in adulthood. In U. Frith (Ed.), *Autism and Asperger Syndrome* (pp. 147–183). Cambridge, UK: Cambridge University Press.
- Tarnai, B., & Wolfe, P. S. (2008). Social stories for sexuality education for persons with autism/Pervasive Developmental Disorder. *Sexuality and Disability, 26*, 29–36. doi :10.1007/s11195-007-9067-3
- Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Philadelphia, PA: Open University Press.
- Thomas, C. (2004). Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research, 6*, 22–36. doi:10.1080/15017410409512637
- Thompkins, R., & Deloney, P. (1995). Inclusion: The pros and cons. *Issues . . . About Change, 4*(3), 1–11. Retrieved June 1, 2013, from <http://www.sedl.org/change/issues/issues43.html>
- Thornton, C., & Underwood, K. (2013). Conceptualisations of disability and inclusion: Perspectives of educators of young children. *Early Years, 33*, 59–73. doi:10.1080/09575146.2012.682975
- Tissot, C. (2009). Establishing a sexual identity—Case studies of learners with autism and learning difficulties. *Autism, 13*, 551–566. doi:10.1177/1362361309338183
- Travers, J., & Tincani, M. (2010). Sexuality education for individuals with autism spectrum disorders: Critical issues and decision making guidelines. *Education and Training in Autism and Developmental Disabilities, 45*, 284–293.

- Tremblay, M., & Pigeon, C. (2004). De la reconnaissance du droit à l'élargissement de l'espace démocratique pour les "personnes présentant une déficience intellectuelle". *Revue Francophone de la Déficience Intellectuelle*, *15*, 133–141.
- Tryon, P. A., Mayes, S. D., Rhodes, R. L., & Waldo, M. (2006). Can Asperger's disorder be differentiated from autism using DSM-IV criteria? *Focus on Autism and Other Developmental Disabilities*, *21*, 2–6. doi:10.1177/10883576060210010101
- Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work*, *11*, 80–96. doi:10.1177/1473325010368316
- Van Bourgondien, M. E., Reichle, N. C., & Palmer, A. (1997). Sexual behavior in adults with Autism. *Journal of Autism and Developmental Disorders*, *27*, 113–125. doi:10.1023/A:1025883622452
- Volkmar, F. R. & Wiesner, L. A. (2003). *Healthcare for children on the autism spectrum: A guide to medical, nutritional and behavioral issues*. Bethesda, MD: Woodbine House.
- Vorhaus, J. (2005). Citizenship, competence and profound disability. *Journal of Philosophy of Education*, *39*, 461–475. doi:10.1111/j.1467-9752.2005.00448.x
- Walker, J. (2004). Parents and sex education—Looking beyond 'the birds and the bees'. *Sex Education*, *4*, 239–254. doi:10.1080/1468181042000243330
- Watson, S., Venema, T., Molloy, W., & Reich, M. (2002). Sexual rights and individuals who have a developmental disability. In D. Griffiths, D. Richards, P. Federoff, & S. Watson (Eds.), *Ethical dilemmas: Sexuality and developmental disability* (pp. 19–52). Kingston, NY: NADD Press.
- Weber, K., & Bennett, S. (2004). *Special education in Ontario schools* (5th ed.). Palgrave, ON: Highland Press.
- Wehmyer, M. L., & Obremski, S. (2013). Intellectual disabilities. In: J. H. Stone, M. Blouin, (Eds.), *International encyclopedia of rehabilitation*. Retrieved March 5, 2103, from <http://cirrie.buffalo.edu/encyclopedia/en/article/15/>
- Werner-Wilson, R., & Fitzharris, J. (2001). How can mothers and fathers become involved in the sexuality education of adolescents? *Journal of HIV/AIDS Prevention & Education for Adolescents & Children*, *4*, 49–59. doi:10.1300/J129v04n01\_05
- Whiteley, P., Todd, L., Carr, K., & Shattock, P. (2010). Gender ratios in autism, Asperger syndrome and autism spectrum disorders. *Autism Insights*, *2*, 17–24. doi:10.4137/AUIS3938
- Winter, E. C. (2003). Developmental disabilities in Ontario's schools. In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (2nd ed., pp. 583–602). Toronto, ON: Ontario Association on Developmental Disabilities.

- Wittgenstein, L. (1986). *Philosophical investigations* (3rd ed.) (G. E. M. Anscombe, Trans.). Oxford, England: Basil Blackwell. (Original work published 1953)
- Wolfe, P. S., & Blanchett, W. J. (2003). Sex education for students with disabilities: An evaluation guide. *Teaching Exceptional Children, 36*(1), 46–51.
- Wolfe, P. S., Condo, B., & Hardaway, E. (2009). Sociosexuality education for persons with autism spectrum disorders using principles of applied behavior analysis. *Teaching Exceptional Children, 42*(1), 50–61.
- Wolfensberger, W. (1977). *The principle of normalization in human services*. Toronto, ON: National Institute of Mental Retardation.
- World Health Organization Working Group. (2002). *Sexual health—Sexuality working definition*. Retrieved June 1, 2013, from [http://www.who.int/reproductivehealth/topics/gender\\_rights/sexual\\_health/en/](http://www.who.int/reproductivehealth/topics/gender_rights/sexual_health/en/)
- Worth, N. (2013). Making friends and fitting in: A social-relational understanding of disability at school. *Social & Cultural Geography, 14*, 103–123. doi:10.1080/14649365.2012.735693
- Wyness, M. G. (1992). Schooling and the normalisation of sex talk within the home. *The British Journal of Sociology of Education, 13*, 89–103. doi:10.1080/0142569920130106
- Yin, R. K. (2003). *Case study research, design and methods* (3rd ed.). Thousand Oaks, CA: Sage.

## Appendices

Appendix A	Sexuality and Autism: A Critical Review of Selected Literature Using a Social-Relational Model of Disability .....	291
Appendix B	Summary of Sexuality Studies about Individuals with Autism Detailed in Literature Review .....	325
Appendix C	Visual Representation of Conceptual Framework and Linkages to Research Questions.....	331
Appendix D	Sample Recruitment Poster (English) .....	332
Appendix E	Sample Recruitment Poster (French) .....	333
Appendix F	Introductory Letter (English) .....	334
Appendix G	Introductory Letter (French) .....	335
Appendix H	Consent to Contact Form (English) .....	336
Appendix I	Consent to Contact Form (French) .....	337
Appendix J	Coding Scheme for Research Questions and Table of Specifications.....	338
Appendix K	Caregiver Consent Form and Survey (English) .....	340
Appendix L	Caregiver Consent Form and Survey (English) .....	355
Appendix M	Youth Consent Form and Survey (English) .....	371
Appendix N	Youth Consent Form and Survey (French) .....	382
Appendix O	Caregiver Consent Form and Interview Rubric (English) .....	393
Appendix P	Caregiver Consent Forma and Interview Rubric (French) .....	400
Appendix Q	Youth Consent Form and Interview Rubric (English) .....	407
Appendix R	Youth Consent Form and Interview Rubric (French) .....	413
Appendix S	Resource List (English) .....	420
Appendix T	Resource List (French) .....	426
Appendix U	Summary of Dimensions of Sexuality Education Modality According to Youth, Caregivers, and as Supported by Extant Texts .....	433

Appendix V	Summary of Sexuality Education Content According to Youth, Caregivers, and as Supported by Extant Texts.....	437
Appendix W	Summary of Manifestations of Sexuality Education According to Youth, Caregivers and as Supported by Extant Texts .....	440
Appendix X	Sexuality Contents of the Revised Ontario Curriculum, Grades 1 to 8: Health and Physical Education (Full and Interim Editions) .....	441
Appendix Y	Sexuality Contents of the Ontario Curriculum, Grades 9 to 12: Healthy Living & Healthy Growth and Sexuality.....	452
Appendix Z	SIECUS Key Concepts and Topics of Comprehensive Sexuality Education .....	454
Appendix AA	Visual Representation of Completed Conceptual Framework with Linkages to Research Questions.....	455
Appendix BB	Summary of Complete Findings .....	457

## Appendix A: Sexuality and Autism: A Critical Review of Selected Literature Using a Social-Relational Model of Disability

*American Journal of Sexuality Education*, 5:328–361, 2010  
Copyright © Taylor & Francis Group, LLC  
ISSN: 1554-6128 print / 1554-6136 online  
DOI: 10.1080/15546128.2010.527237



# Sexuality and Autism: A Critical Review of Selected Literature Using a Social-Relational Model of Disability

NATHALIE A. GOUGEON, MS Ed

*Department of Education, University of Ottawa, Ottawa, Canada*

*This article provides a summary of selected research conducted on the sexuality, as well as sexual knowledge and behaviors of individuals with autism over the past 20 years. The discussion section reviews the research according to the following recurrent themes: the importance of sexuality in the lives of individuals with autism, the discourse of problematic sexuality, and the difficulty in translating knowledge into practice. Using Reindal's (2008) pragmatic social-relational model of disability, this article provides an analysis of the research and offers suggestions for future inquiries in this area.*

**KEYWORDS** *Autism, disability, inclusion, sexuality*

### INTRODUCTION

The sexuality of individuals with disabilities has long been a controversial issue. Historically, the sexuality rights of individuals with disabilities have been ignored, denied, and suppressed (Craft, 1994; Di Giulio, 2003; Griffiths, 2003; Monat-Haller, 1992; Niederbuhl & Morris, 1993; Shakespeare, Gillespie-Sells, & Davies, 1996), with the starkest example being the Eugenics movement (Greenspan, 2002; Plaute, Westling, & Cizek, 2002; Radford & Park, 2003; Sobsey, 1994; Watson, Venema, Molloy, & Reich, 2002; Winter, 2003). Following the Eugenics movement was the era of deinstitutionalization and mainstreaming. This era prompted the closure of large scale institutions for individuals with disabilities in the United States, Canada, and elsewhere (Radford & Park, 2003; Wolfensberger, 1977); this era was strongly influenced

---

Address correspondence to Nathalie A. Gougeon, Department of Education, University of Ottawa, 145 Jean-Jacques-Lussier, Box 15b, Ontario, K1N 6N5, Canada. E-mail: [nathalie.gougeon@uottawa.ca](mailto:nathalie.gougeon@uottawa.ca)

by the normalization movement. Normalization involved improving the living arrangements, employment opportunities, legal rights, and self-determination for individuals with disabilities, essentially aiming to make these aspects of life equal to the rest of society (Bacharach, 1985; Gardner & Chapman, 1990). The movement of normalization, which followed on the heels of the civil rights and feminist movements, was the beginning of what we today call the inclusion movement (Radford & Park, 2003). The advent of the inclusion movement, which views all individuals as fully participating members of society, has allowed for an increased recognition of the fundamental rights for individuals with disabilities. The inclusion movement is more comprehensive than the normalization movement, since it views systems as needing to adapt to the needs of the individual rather than individuals needing to conform to established systems. In this sense, it is not up to the individual to become more “normal,” but rather it is up to the system to be more “inclusive” of all people. Despite the increased recognition of the fundamental rights of individuals with disabilities that transpired from the inclusion movement, the recognition of socio-sexual rights continues to lag behind other areas in the move towards full inclusion.

### Autism: Particularities and Socio-Sexuality Education Needs

Because of the particular deficits that characterize autism,<sup>1</sup> individuals who have autism are especially prone to having their sexuality rights curtailed. Autism is a unique neurological disorder that affects approximately one in 110 children in the United States. While its origins are unknown, most experts agree the causes stem from biologic, genetic, and environmental factors (Centers for Disease Control and Prevention, 2010). Autism, as a “spectrum” disorder, manifests in various ways and can present any number of characteristics. Consequently, these characteristics can range from very mild (e.g., as in Asperger syndrome or “high-functioning” autism) to very severe (e.g., as in “classic” autism or pervasive developmental disorders). The following diagnostic criteria are typically used to identify autism: qualitative impairments in social interactions and communication; restrictive repetitive stereotyped patterns of behavior; and delays or abnormal functioning before age 3 in the area of social, communicative, or imaginary play (DSM-IVR) (American Psychiatric Association, 2000). Statistically, approximately 70% of persons who have autism also have an intellectual disability; conversely, 40% of persons who have an intellectual disability also have autism (e.g., Ghaziuddin, Ghaziuddin, & Gredden, 2002; La Malfa, Lassi, Bertelli, Slavini, & Placidi, 2004).<sup>2</sup> There is, therefore, often a close relationship between intellectual disability and autism. However, the unique characteristics of autism are such that the needs of individuals with autism, especially in the area of socio-sexuality education, are vastly different from those with an intellectual

disability alone. Because the unique characteristics of autism are social, communicative, and behavioral in nature, individuals with autism require targeted intensive adapted educational practices specific to their impairment (Aylott, 2000; Barnhill, 2007; Gerhardt, 2006; Hatton & Tector, 2010; Howlin, 1997; Kalyva, 2010; Koller, 2000; Nichols & Blakeley-Smith, 2010; Realmuto & Ruble, 1999; Sullivan & Caterino, 2008; Travers & Tincani, 2010). In view of that, persons with autism need comprehensive and personalized curricula that directly teach what is often learned incidentally or naturally by other individuals (for more information regarding curricula, see Hatton & Tector, 2010; Hénault, 2006; Meister, Norlock, Honeyman, & Pierce, 1994; Mitchell, 2010; Sullivan & Caterino, 2008; Wolfe & Blanchett, 2003; Wolfe, Condo, & Hardaway, 2009; Wrobel, 2003). These incidentally learned skills, behaviors, and knowledge are also known as the “hidden curriculum” (Gougeon, 2009; Lavoie, 2005; Myles & Simpson, 2001). For example, individuals with autism frequently necessitate overt teaching of facial expressions, emotions, and other nonverbal decoding skills, as well as training in initiating, maintaining, and ending social interactions with peers (e.g., Attwood, 2004; Chin & Bernard-Opitz, 2000; Gerhardt, 2006; Rogers, 2000; Travers & Tincani, 2010). They may not necessarily discriminate between a public or private setting, or they may not have a well developed ‘theory of mind’ (i.e., be able to understand a different perspective from their own) (e.g., Baron-Cohen, 2001; Chin & Bernard-Opitz, 2000). Thus, they may present with maladaptive socio-sexual behaviors such as undressing or masturbating in public areas, misinterpreting relationship boundaries, skipping steps toward intimacy, making improper comments, or acting in other socially inappropriate ways (Gray, Ruble, & Dalrymple, 2000; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Hénault, 2006; Howlin, 2004; Mitchell, 2010; Ray, Marks, & Bray-Garretson, 2004).

As youth with autism mature, their social and sexual deficits may present them with significant problems in developing and maintaining intimate relationships (though some still do so with success, particularly individuals with a diagnosis of Asperger syndrome), in engaging in socially appropriate behaviors, in gaining and maintaining employment, and more generally, in being accepted as valued members within their community (Sullivan & Caterino, 2008; Travers & Tincani, 2010; Tremblay & Pigeon, 2004). These issues touch at the core meaning of inclusion since the limited extent individuals with autism are able to integrate as fully accepted social and sexual beings within their community can result in long-standing negative effects, including depression, anxiety and other mental health issues, low self-esteem, and isolation (Aylott, 2000; Barnhill, 2007; Ghaziuddin et al., 2002; Hatton & Tector, 2010; Koller, 2000; Ozonoff, Garcia, Clark, & Lainhart, 2005). As such, their needs in these areas must be addressed forthrightly through the provision of broad, appropriate, relevant, and effective socio-sexuality<sup>3</sup> education (Meister et al., 1994). Adapted curricula and related resources exist that target

the specific socio-sexual needs of individuals with autism, as do proven effective methods to teach these skills (e.g., Champagne & Walker-Hirsch, 1993; Durocher & Fortier, 1999; Hénault, 2006; Kempton, 1993; Koller, 2000; Lemay, 1996; Mitchell, 2010; Schopler, 1997; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Wolfe & Blanchett, 2003; Wolfe et al., 2009; Wrobel, 2003). Some common themes emerge from the limited research on effectively teaching socio-sexuality education to individuals with autism. Many advocate the use of established evidence-based strategies, such as those founded in Treatment and Education of Autistic related Communication-handicapped Children (TEACCH) methodology (Schopler, 1997; Sullivan & Caterino, 2008) or in applied behavior analysis (ABA) (Gerhardt, 2006; Wolfe & Blanchett, 2003; Wolfe et al., 2009). Many also stress the importance of personalizing the curriculum and methodology to the individual, as well as of providing individual or small group instruction (Aylott, 2000; Gerhardt, 2006; Hellemans et al., 2007; Hénault, 2006; Koller, 2000; Lawson, 2005; Sullivan & Caterino, 2008; Tarnai, 2006; Waddell & Rowe, 2006). Some strategies used to personalize the curriculum include Social Stories™ (Gray, 2002; Ray et al., 2004; Tarnai & Wolfe, 2008), comic strip conversations (Gray, 1994; Ray et al., 2004), and video modeling and task analyses (Wolfe & Blanchett, 2003; Wolfe et al., 2009), many of which are ABA based. Also central to the success of any socio-sexuality curriculum is ensuring a highly structured environment, using concrete terminology, making the curriculum personally relevant, offering repeated opportunities to learn, master, and practice the skills, teaching discrimination, using reinforcement schedules, and ensuring generalization of skills across people and settings (Gerhardt, 2006; Heward, 1987; Mitchell, 2010; Schopler, 1997; Sullivan & Caterino, 2008). Whether individuals with autism receive such a socio-sexuality education depends mainly on the decisions made by those stakeholders who act on their behalf and for their welfare. As it currently stands, a gap exists between the perceived need for socio-sexuality education and its actual provision. Why does this gap continue to exist? Ostensibly, the reason may well rest with the many negative stereotypes that still abound regarding the sexuality of persons with disabilities (Griffiths, 2003). Individuals with disabilities, including those with autism, continue to be viewed by the general population as being asexual, childlike, hyper-sexual, or deviant (Craft, 1994; Di Giulio, 2003; Gougeon, 2009; Griffiths, 2003; Monat-Haller, 1992; Niederbuhl & Morris, 1993; Radford & Park, 2003; Shakespeare et al., 1996). There is a common misconception that individuals with autism are asexual or uninterested in sexuality; another misconception is that individuals with autism are sexual but that shared sexuality is of interest to them only insofar as the other person is a means to an end (Aylott, 2000; Koller, 2000; Konstantareas & Lunsby, 1997; Lawson, 2005; Ousley & Mesibov, 1991; Stokes & Kaur, 2005; Sullivan & Caterino, 2008; Van Bourgondien, Reichle, & Palmer, 1997). Another possible explanation for why the gap between need and provision

exists is because education has historically been associated with academic skills and, while sexuality has become a more accepted component of the standard curriculum, the teaching of social and sexual skills has not. In view of that, educational stakeholders may be reluctant to include topics that have historically been deemed outside of the scope of standard curriculum. However, it is precisely because individuals with autism do not incidentally learn the social and sexual skills necessary for full inclusion that this curriculum is vital to their long-term social success. Finally, when sexuality does come to the forefront as a skill to be taught, it often remains shrouded in a discourse of problematic behavior management and/or protection (Ousley & Mesibov, 1991; Realmuto & Ruble, 1999; Sullivan & Caterino, 2008; Van Bourgondien et al., 1997). To be sure, the sexuality of individuals with autism is often seen as either a problem to be managed or a child-like vulnerability in need of protection.

### A Social-Relational Model of Disability

Is there a way to explain and reconcile these realities? One proposed theoretical framework is Reindal's (2008) social-relational disability model (Norwich, 2002; Reindal, 2008). Although not developed specifically for the topic of sexuality and sexuality education for individuals with autism, it is a model that can address these issues well. In the field of education, people often take on multiple roles, be it as administrators, teachers, advocates, researchers, or even students. As a result, practice is founded on theories that are relevant to one's lived experience. For this reason, Reindal's social-relational disability model provides a means of reconciling the dueling positivist and socio-constructivist epistemologies of disability, and provides a practical theory that can be applied to one's research, practice, and life.

Reindal's two-pronged approach provides a pragmatic way of addressing the needs of, and barriers faced by, individuals with autism. The first prong identifies the actual biological or somatic impairment that exists in the individual. This impairment causes certain constraints and perceived effects on the individual, in this case the real social, communicative, and behavioral deficits that the individual with autism presents with. The second prong is the presence of social barriers. The combination of impairment(s) and social barrier(s) results in the experience of disability. This disability functions as a form of oppression or exclusion in the sense that it prevents the individual from participating as a member of society to his or her fullest extent due to outside factors. This approach does not divide "additionality" (actual needs of the individual incurred by the biological impairment), that is, the medical view, and "inclusivity" (the removal of social barriers that may prevent an individual from otherwise participating within the community), that is, the socio-constructivist view (Norwich, 2002; Reindal, 2008). The adoption of

such an approach allows for a holistic conceptualization of the individual with autism as a member within a community and, as such, is a truly socially inclusive model. Such a model can help to identify when only one aspect of disability is being addressed in a given situation and can be used to help provide necessary accommodations as well as remove societal obstacles. This can be particularly useful in addressing the sexuality of individuals with autism, as both identified needs and barriers continue to persist, preventing their needs and rights from being fully met.

The ensuing sections of this article provide an overview of selected recent research that has been specifically conducted on the sexuality, as well as sexual knowledge and behaviors of individuals with autism. Subsequent to this overview, Reindal's (2008) social-relational model of disability is used to critique the research according to these recurrent themes: the importance of sexuality in the lives of individuals with autism, the discourse of problematic sexuality, and the difficulty that exists in translating knowledge into everyday practice. The article ends with suggestions for future research in the field of sexuality and autism.

## METHOD

Initially, the author conducted a search of the databases Academic Search Complete, CINAHL, Education Full Text, Educator's Reference Complete, ERIC, MEDLINE, and PsycINFO using the key word search terms "autism" or "Asperger" paired with either "socio-sexuality," "sex/education," or "sexuality/education." The author looked for research articles published between 1990 and 2010<sup>4</sup> in peer-reviewed journals and in English. Once this was completed, a second search was conducted by consulting primary sources cited within the articles that pertained to the subject under investigation. Sources were included based on relevance to the subject, as well as meeting the aforementioned criteria. As there has been a significant amount of literature produced on sexuality in people with an intellectual disability, but far less written specifically on this topic for individuals with autism (Travers & Tincani, 2010), and since the needs of individuals with autism are different than those with an intellectual disability, the focus of the literature review was kept to research germane to autism. In total, 13 studies were retained for review.

## RESULTS

A total of 13 studies were retained for review, which varied in a number of ways, including by method, sample size, location, and focus. Key information about the studies included in this review can be found in Table 1. This

**TABLE 1** Summary of Studies Examining Sexuality (Knowledge, Interest, and Behaviors) in Individuals with Autism

Study	Sample Size and Description	Location	Research Methodology	Major Findings
	<i>Self-Perceptions</i>			
Ousley and Mesibov (1991)	41 individuals: 21 with “high-functioning” autism (11 males, mean IQ = 84.4; 10 females, mean IQ = 73.9) 20 with a “mild to moderate” intellectual disability (10 males, mean IQ = 56.9; 10 females, mean IQ = 54.6)	North Carolina, USA	Questionnaire and structured interview administered by examiner (orally) and completed verbally	<ul style="list-style-type: none"> <li>– Similar levels of interest and knowledge in sexuality across both groups</li> <li>– Significantly less sexual experiences (personal or shared) for individuals with autism</li> </ul>
Konstantareas and Lunsky (1997)	31 individuals: 15 with autism (9 males; 6 females) 16 with an intellectual disability (8 males; 8 females)	Southern Ontario, Canada	Questionnaire and structured interview (with visual aids) administered by examiner (orally) and completed verbally/with gestures	<ul style="list-style-type: none"> <li>– Similar levels of interest in sexuality across both groups</li> <li>– Increased sexual knowledge related to increased negative attitude towards sexuality</li> <li>– Lack of complex understanding relating to sexuality</li> <li>– Variety of sexual experiences and behaviors reported</li> </ul>
	<i>Perceptions of Others</i>			
Ruble and Dalrymple (1993)	100 caregivers reporting on 100 individuals with autism (individuals with autism consisted of 68 males and 32 females)	Indiana, USA	Self-administered written questionnaire completed by parent or legal guardian	<ul style="list-style-type: none"> <li>– Presence of sexual behaviors (“appropriate” and “inappropriate”) across sample</li> <li>– Verbal skills positively correlated to sexual knowledge and understanding</li> <li>– Parental concern regarding misinterpretation of behaviors, teaching sex education, potential negative consequences related to sexuality</li> </ul>

Van Bourgondien et al. (1997)	Caregivers reporting on 89 individuals with autism (individuals with autism consisted of 72 males and 17 females)	North Carolina, USA	Self-administered written questionnaire completed by group home staff	<ul style="list-style-type: none"> <li>- Presence of sexual behaviors in 74% of sample</li> <li>- Presence of person-directed sexual behaviors in 34% of sample</li> <li>- Limited sexual expression for most individuals with autism</li> </ul>
Stokes and Kaur (2005)	74 parents reporting on 23 children with 'high-functioning' autism or Asperger syndrome (17 male; 6 female); and 50 neurotypical children (33 males; 17 females)	Undisclosed location, Australia	Self-administered written questionnaire completed by parent or legal guardian	<ul style="list-style-type: none"> <li>- Compared to neurotypical children, children with autism displayed more socially inappropriate behaviors, demonstrated less privacy skills, knew less about sex education, and had parents who were more concerned about their long-term outcomes</li> <li>- Parental concern increased as children with autism aged; concern decreased as neurotypical children aged</li> <li>- A developmental lag appears to be present in children with autism</li> </ul>
Stokes et al. (2007)	63 parents reporting on individuals 25 with 'high-functioning' autism (16 males; 9 females); and 38 neurotypical individuals (32 males; 6 females)	Undisclosed location, Australia	Self-administered written questionnaire completed by parent or legal guardian	<ul style="list-style-type: none"> <li>- Sources of information on social, romantic, and sexuality skills less likely to come from peers for individuals with autism</li> <li>- Individuals with autism had lower levels of social functioning than neurotypical peers</li> <li>- Individuals with autism exhibited more atypical and inappropriate social and romantic behaviors, exhibited behaviors towards more inappropriate targets, and for longer periods of time</li> </ul>

*(Continued on next page)*

**TABLE 1** Summary of Studies Examining Sexuality (Knowledge, Interest, and Behaviors) in Individuals with Autism (*Continued*)

Study	Sample Size and Description	Location	Research Methodology	Major Findings
Hellemans et al. (2007)	17 caregivers reporting on 24 male individuals along the autism spectrum: (autism: 14; pervasive developmental disorder—not otherwise specified, 6; Asperger syndrome, 4)	Flanders, Belgium	Investigator based, semi-structured interview of caregiver	<ul style="list-style-type: none"> <li>– High rates of interest in sexuality (96%)</li> <li>– Discrepancy between theoretical knowledge and its application</li> <li>– Variety of sexual behaviors present</li> <li>– Many displayed an interest in sexual relationships with others (42%)</li> </ul>
Kalyva (2010)	56 teachers reporting on 76 children: 56 children with “low”functioning’ autism (38 males; 18 females); 20 children with “high functioning” autism (16 males; 4 females)	Mainland, Northern Greece	Self-administered written questionnaire completed by teacher	<ul style="list-style-type: none"> <li>– Appropriate social and privacy behaviors, as well as knowledge of privacy and sexuality all positively correlated with level of functioning</li> <li>– Teachers expressed more concern over long-term outcomes for children with “higher functioning” autism</li> </ul>
Nichols and Blakeley-Smith (2010)	Focus group participants: 21 parents (1 male; 20 females) of children with autism (13 males; 8 females) Parent education groups: Parents of 10 children with autism (5 males; 5 females)	Colorado, USA	Focus groups with parents (audio recording; notes, analysis); pretest/posttest effectiveness evaluation of sexuality education curriculum	<p>Focus groups:</p> <ul style="list-style-type: none"> <li>– Main themes included: finding meaning of “healthy sexuality” for individuals with autism; desire for relationships; significance of social impairments; exploitation prevention; multistakeholder support; parent resources Parent education groups:</li> <li>– Many parental goals met</li> <li>– Increased comfort in all areas</li> </ul>

*Sexuality Case Studies*

Galluci et al. (2005)	1 male individual with Asperger syndrome	Maryland, USA	Case study (report provided by authors—no description of sources)	<ul style="list-style-type: none"> <li>– Gender identity disorder was present in individual</li> <li>– Propose pharmacological intervention targeted at obsessive compulsive disorder to address gender identity disorder</li> </ul>
Tissot (2009)	6 cases involving 7 individuals with autism (6 males; 1 female)	South of England, UK	Case studies (analysis of meeting notes and student progress notes; staff interviews; observations)	<ul style="list-style-type: none"> <li>– Presence of problematic sexual behaviors addressed through 6-step multi-stakeholder program</li> <li>– Varying degrees of success in reducing problematic behaviors and increasing appropriate behaviors in 5 out of 6 cases</li> </ul>
Griffin-Shelley (2010)	1 male individual with Asperger syndrome	Pennsylvania, USA	Case study (report provided by author; with additional information from family, individual, and previous psychological assessments)	<ul style="list-style-type: none"> <li>– Presence of problematic sexual behaviors</li> <li>– Residential treatment provided limited success</li> <li>– Ongoing issues remained post-discharge, including risk of reoffending and ongoing problematic sexual behaviors</li> </ul>

---

section will examine the different studies, their major relevant findings, and their implications for the field of sexuality and autism.

### Self-Perceptions in Individuals with Autism

There is a common misconception that individuals with autism are emotionless and/or that they are unable to experience attachment toward others; therefore, they cannot fall in love (Aylott, 2000; Lawson, 2005; Ousley & Mesibov, 1991; Van Bourgondien et al., 1997). Accordingly, research that has assessed the self-perceptions of individuals with autism toward their own sexuality has been important in debunking this myth. Few studies have examined the self-perceptions of individuals with autism toward their own sexuality. Among the research are two studies, Ousley and Mesibov (1991) and Konstantareas and Lunsby (1997), that have compared the sexual knowledge and attitudes of individuals with autism to those with an intellectual disability alone. In a U.S. study conducted by Ousley and Mesibov (1991), knowledge, interest, and experience relating to sexuality and dating in “high-functioning” adults with autism were assessed and compared to individuals with a “mild to moderate” intellectual disability. While the terms high-functioning autism and mild to moderate intellectual disability were not defined, participants’ mean IQ scores were identified for both groups (see Table 1). In addition, participants were selected based on their ability to function with some degree of independence at home or at work and on their ability to comprehend the questionnaire. The researchers adapted tools that had been previously developed for use with individuals with an intellectual disability by paring the number of items from 100 down to 31. Questions were chosen for their precision, frankness, and lack of redundancy. The questionnaire was divided into two sections: a vocabulary section (used to assess knowledge), which used a summative rating-scale in which points assigned for completeness and accuracy of answers given; and a multiple-choice section, which touched upon sexual and dating experiences and interest in sexual activities. Results in this study indicated that males in both groups were more interested in sexuality and dating than females. Sexual knowledge and interest were the same for individuals with autism as for individuals with an intellectual disability. However, individuals with autism had significantly less sexual experience (defined as multiple occurrences of either extended hugging and kissing of a nonrelative of the opposite sex, behavior beyond hugging and kissing, or masturbation) than the individuals with an intellectual disability alone. The authors posit that individuals with autism may experience a significant amount of sexual frustration because of the gap between interest and experience. They argue that increased adapted socio-sexuality education may help to address this problem.

A similar study conducted some years later in Canada by Konstantareas and Lunskey (1997) also assessed the sexual knowledge, interest, and experience of individuals with autism and individuals with an intellectual disability (termed “developmental delay” in the text). Unique to this study was the range of abilities represented in the sample, including high-functioning, as well as moderate and lower-functioning individuals across both the autism and intellectual disability groups. Levels of functioning were determined according to the Developmental Profile (DPII) score obtained by each individual (Alpern, Boll, & Shearer, 1984). Visual aids were used to increase the likelihood of comprehension of the topics addressed in the questionnaire and interview. The tools used for this study were adapted from Ousley and Mesibov (1991), as well as Wish, McCombs, and Edmondson (1980); items were chosen for their simplicity and frankness. Areas covered included knowledge of sexual vocabulary, socio-sexual experiences, socio-sexual attitudes, and socio-sexual interests. There were no differences in results based on DPII cognitive functioning level that were attributable to group or gender; however, there was a marked difference in both social and communication functioning levels based on group, with individuals with autism scoring significantly lower. While both groups demonstrated awareness of some socio-sexual terminology (e.g., gender labels, “pregnancy,” “vagina,” “ejaculation”), many demonstrated a lack of complex understanding related to this same terminology. Individuals with autism reported higher levels of endorsement for various types of socio-sexual behaviors (e.g., birth control, sexual activity, intercourse, homosexuality, adultery). This group also expressed having had a variety of sexual experiences, although the authors caution that the conceptualizations of the terms “intercourse” and “masturbation” may have been different than the norm. It was found that individuals with autism express similar levels of interest in sexuality as individuals with an intellectual disability alone. The study also found that negative attitudes toward sexuality were proportional to the amount of knowledge individuals had received. The authors suggest that this may be in part due to the discourse of fear and protection that is usually associated with any dissemination of knowledge to people with disabilities. As a result, participants may have responded based on their knowledge of the potential negative consequences of sexual behavior alone.

As the published research search results show, few studies have used self-reporting to assess the knowledge, interest, and behaviors of individuals with autism regarding sexuality. Why such a paucity of information in this area? Realmuto and Ruble (1999) argue that self-reports may be difficult to obtain from this population and that “this lack of information may be due to the nature of autism, as this disability often restricts self-report as a source of information about most areas of emotional interest” (p. 126). Whatever the reasons, the bulk of research that has addressed the topic of sexuality for

individuals with autism has been from the perception of others rather than the individuals themselves. It is this research that we shall now examine.

### Perceptions of Others

Research conducted by Ruble and Dalrymple (1993) and Van Bourgondien, Reichle, and Palmer (1997) looked at caregiver (parent or professional) assessment of sexual knowledge and behaviors of individuals with autism. Ruble and Dalrymple (1993) obtained caregiver input regarding the sexual awareness (e.g., knowledge of body parts and function, respect and/or desiring personal privacy, discriminating public and private behaviors), education, and behaviors of individuals with autism living in Indiana. Surveys were completed by parents or other legal guardians of individuals with autism aged between 9 and 39 years. A Sexuality Awareness Survey (SAS) was developed specifically for this study. This questionnaire was divided into the following areas: socio-sexual awareness, sex education, sexual behaviors, parental concerns, and desired information on sexuality. Verbal skills were seen to be positively correlated with knowledge and understanding of sexual topics. Caregivers reported having taught a variety of skills related to privacy and appropriate behaviors (e.g., where to undress, where and when it is appropriate to touch one's private parts, knocking on closed doors) in a number of ways to their children with autism, with males being taught rules more often than females. Also, a variety of sexual behaviors, including inappropriate behaviors (e.g., touching private parts and/or masturbating in public, removing clothing in public, not wanting to touch their penis while urinating, masturbating with unusual objects such as socks), were noted as occurring in individuals with autism, regardless of verbal abilities. It was found that parents and caregivers were most concerned about the misinterpretation of their children's behaviors as being sexual, or that their sexual behaviors would be misunderstood. In addition, concerns about pregnancy and sexual abuse were raised by caregivers. Parents were also concerned about how to effectively teach socio-sexuality education to their children.

In contrast, Van Bourgondien et al.'s (1997) survey was conducted with professional residential caregivers working with individuals with autism in North Carolina. This study looked at the sexual behaviors of persons with autism, as well as the policies on sexuality and sex education in these settings. Caregivers reported on individuals with autism ranging between the ages of 16 and 59. The individuals represented a range of ability levels, from mild to severe impairment. Although no explicit criteria are given, the authors state that intellectual impairment was measured according to reported "degree of autism, degree of mental retardation (sic), and verbal abilities" (p. 116). Of note was the high rate (90%) of individuals deemed "legally incompetent" (meaning that they had been legally deemed incapable of making decisions on their behalf and were therefore assigned a legal

guardian) included in the study. Indeed, research in this field often focuses on individuals with higher levels of functioning, thus it is a notable exception (along with Konstantareas & Lunskey, 1997) that a broader sample of this population was included. Surveys were sent to 35 group homes for individuals with autism and 107 residential homes for individuals with developmental disabilities. Of the group homes for individuals with autism, 80 questionnaires were completed and returned, while of the group homes for individuals with developmental disabilities, nine questionnaires were completed and returned. Questionnaires were divided into four sections. The first section used a 5–6 point scale, touched upon sexuality topics (including masturbation with and without objects, arousal from visual stimuli without physical contact, and interpersonal behavior leading to arousal) and was based on a tool previously created for this purpose (Haracopos & Pedersen, 1992). The second section asked about the sexuality policies and training procedures used in a given group home, and the third section used a pre-existing checklist to gather information about the occurrence of aberrant behaviors (e.g., irritability, crying, social withdrawal, stereotypy, inappropriate speech) by the individual (Aman & Singh, 1986). The fourth section collected demographic information about each individual with autism. The study found that most individuals with autism do exhibit sexual behaviors, with fully 76% of the sample exhibiting some sexual behavior and 68% of the sample masturbating. Many of the sample population experienced sexual frustration, and a number of individuals demonstrated inappropriate sexual behaviors (e.g., sexual behaviors directed toward staff, masturbating outside of the residential setting). The study also found that many individuals with autism exhibited sexual interest toward other people (34% of the sample), which adds to the growing body of literature that dispels the commonly held myth that this population is not interested in others. The researchers found that of the 14 responding homes that provided information on their sexuality education and policies, 6 programs provided training to staff regarding sex education or counseling, 12 programs provided sex education, and only 4 programs allowed individuals with autism to engage in any sexual contact beyond kissing. Thus, among the small percentage of respondents that did provide information on these topics, few individuals under their care would be allowed to experience a shared sexuality. The study found no correlation between aberrant behaviors and sexual dysfunction (e.g., inability to achieve orgasm through masturbation; appearance of frustration vis-à-vis inability to achieve orgasm) and thus refutes the previously posited argument that sexual frustration will increase incidences of maladaptive behavior in individuals with autism.

In an Australian study by Stokes and Kaur (2005) that followed in the steps of Ruble and Dalrymple (1993), a survey was conducted with parents of children ages 10–15 with high-functioning autism or Asperger syndrome and neurotypical children regarding their appropriate socio-sexual behaviors

(e.g., socialization outside of family and school, privacy behavior), inappropriate socio-sexual behaviors (e.g., masturbating in public, behaving in a socially unacceptable way toward person of romantic interest), and their sex education (e.g., knowledge of privacy rules, hygiene, appropriate social behaviors, and sexual responses). The tool developed for this study, the Sexual Behavior Scale (SBS), was based on tools previously developed in this field (Haracopos & Pedersen, 1992; Ruble & Dalrymple, 1993). It was divided into five sections which addressed the topics of privacy, social and sexual behaviors, sex education, and parental concerns (e.g., misinterpretation of their child's behavior, long-term outcomes for their children). The tool used a variety of 3- or 4-point rating scales and dichotomous responses, and gathered demographic information for comparison purposes. The individuals with high-functioning autism in the study scored lower than the neurotypical adolescents in all domains. As age increased, it was found that neurotypical adolescents improved in the areas of knowledge of privacy and privacy behaviors, knowledge of sex education, and sexual behavior. The same was not found for individuals with high-functioning autism. Of interest was the finding that parents of both groups held similar concerns for their children at 10 years old, but while concerns decreased in parents of neurotypical children as they aged, concerns increased in parents of children with autism. Also of interest was the noted increase in social behaviors (e.g., engaging in social activities with peers outside of family and school) in children with autism as they aged, while a noted decrease in social behaviors in neurotypical children was found. Overall, the authors found that there seems to be a developmental lag in children with high-functioning autism that manifests itself through socially and sexually inappropriate behaviors and gaps in knowledge. Such a finding points toward a need for targeted socio-sexuality education for individuals with autism.

Another Australian study by Stokes, Newton, and Kaur (2007) compared parents' views regarding the social, romantic, and stalking behaviors of children with and without high-functioning autism between the ages of 13 and 36. A questionnaire, the Courting Behavior Scale (CBS), was designed specifically for this study and was based on previous research in the field (Haugaard & Seri, 2004; McCann, 2000; Spitzberg & Cupach, 2003), including the authors' own tool developed for the afore-mentioned study (Stokes & Kaur, 2005). The questionnaire examined parental input regarding their children's: social functioning (e.g., interest in, and actual, peer relationships; level of meaningful relationships; knowledge about initiation), as well as romantic functioning (e.g., desire for, and knowledge about, intimate or sexual relationships; knowledge and experience of sexual behaviors). It also sought demographic information for comparative purposes. This tool used similar types of questions as in the previous study. It was found that neurotypical individuals learned more of their social and romantic skills and knowledge from their peers than did individuals with autism. Individuals with autism

had lower levels of social functioning than their neurotypical peers but did not display a difference in romantic functioning. However, when the effect of age was controlled for, individuals with autism had a romantic level of functioning that was significantly lower than their neurotypical peers. Moreover, increased age resulted in increased social functioning in neurotypical individuals, while for individuals with autism it was an increase in skills and knowledge from peers that predicted increased social functioning (rather than age). Such an outcome points to the need to provide the “hidden” curriculum to this group of individuals, if they are to increase their social and sexual functioning within society. Results differed for individuals with autism regarding their behaviors in initiating contact and pursuing individuals for social or romantic reasons. Individuals with autism exhibited a number of atypical behaviors (touching inappropriately, monitoring others’ activities, and following) and displayed them less discriminately and more often toward inappropriate targets (e.g., strangers, celebrities). Individuals in the autism group also tended to pursue their non- or negatively responding targets for longer periods of time than their neurotypical cohort, behaviors which can entail serious legal consequences. These findings also point to the need for the overt teaching of the subtle rules of behavior that exist in socio-sexual interactions with others, a curriculum that is usually excluded from regular education.

Yet another study that looked at the perceptions of others was conducted by Hellemans, Colson, Verbraeken, Vermeiren, and Deboutte (2007). In this study, input from caregivers of male adolescents and young adults (ranging between 15 and 21 years) with autism living in an institutional setting in Belgium was obtained. The researchers investigated theoretical and practical knowledge regarding self-care, socio-sexual skills, behaviors, and problems in males with high-functioning autism residing in an institution. Five institutions were included in this research project. Subjects were excluded if they had a history of sexual abuse or had additional impairments other than autism. Caregivers were interviewed using the *Interview about Sexuality in Autism* tool (Hellemans & Colson, unpublished; cited in Hellemans et al., 2007). The tool was divided into three sections: theoretical and practical knowledge of self-care and socio-sexual skills; actual sexual behavior; presence of autistic features of sexual behavior (defined in the study as repetitive patterns of sexual behavior and sensory fascinations affecting sexual behavior). Questions were answered via rating scales, dichotomous responses, or open-ended responses. Theoretical knowledge about self-care and socio-sexual skills was moderate to good for most individuals; however, the application of these skills was consistently poorer than their theoretical knowledge. Ninety-six percent of individuals showed interest in sexuality. Many individuals had displayed a variety of sexual behaviors (e.g, touching others, kissing others, touching themselves, masturbating), 42% of individuals had expressed a desire for intimate relationships with others, and 21%

had expressed frustration about not being able to establish a relationship. As with Konstantareas and Lunsky (1997), these data demonstrate that individuals with autism are sexual beings with sexual interests. A small percentage of individuals had attempted or had experienced intercourse. Sexual orientation was known to caregivers for 75% of the individuals. Of those whose sexuality was known, 78% were heterosexual, 6% were homosexual, and 17% were bisexual. Regarding autistic features present in sexual behaviors, the researchers found that some individuals expressed a particular interest in objects (e.g., hair, lingerie), personal characteristics (e.g., eye tics, pronounced personal smell), or sensory stimulations (e.g., odors, type of music) that were or potentially were associated with sexuality. Of the 24 individuals, one met diagnostic criteria for pedophilia and had previously been legally prosecuted as such, while another individual met diagnostic criteria for fetishism. One particularly concerning finding was that a total of 29% of subjects were described as having severe sexual problems. The authors of this study noted that sex education, along with training in socio-sexual skills and individual counseling were included as part of the curriculum provided to this group. Socialization opportunities were also provided to individuals both within and outside of the institution. Individuals in this study continued to demonstrate a gap in translating theory into practice regarding appropriate socio-sexual skills. Many individuals also demonstrated either an inability to recognize, or a simple disregard for, the consequences of their unwanted sexual contacts with others. This issue poses a serious problem in terms of one's ability to fully integrate as a valued member of a community and indeed may involve serious legal ramifications if such behaviors are not addressed and managed. Again, such a finding points to the need for adapted socio-sexuality education that targets those specific social and sexual skills that tend to be outside the regular curriculum because they are assumed to be learned incidentally and naturally.

Recently, a study by Kalyva published in 2010 was conducted on the perceptions of teachers towards children (aged 7 to 14 years) across the autism spectrum in Greece. This study used an adaptation of the Stokes and Kaur (2005) Sexual Behavior Scale. As in Stokes and Kaur, it looked at social behavior, privacy, sex education, and sexual behavior. Rather than assessing parental concerns, this study looked at teachers' concerns. Only 12.5% of teachers reported feeling confident that they could provide sexuality education to their students with autism. According to teacher perception, a positive correlation existed between children's level of functioning and appropriate social behavior; the same was true for awareness of privacy rules and privacy seeking behaviors. Teachers also reported that children with higher functioning autism had a greater understanding of sexuality issues and received more sex education than their lower functioning peers. They also perceived children with lower functioning autism as having a history of less appropriate sexual behaviors. Despite these other findings, teachers

expressed more concern toward the misinterpretation of sexual behavior and long-term socio-sexual outcomes for the higher functioning group than for the other group. Another recent study by Nichols and Blakeley-Smith (2010) has looked at parents' perspectives, concerns, and needs regarding the sexuality of their children (ages 8–18) along the autism spectrum, as well as designed, implemented, and evaluated a pilot sexuality education program designed to help prepare parents address these issues. Single focus groups were held and touched on the following topics: hopes for child's future, as it relates to sexuality/relationships; fears and concerns about child's sexuality; relevance of sexuality education for child; information/help related to sexuality needed to be able to teach child; presence of community supports to address sexuality issues of child. A number of themes emerged from the focus group that was used to guide the development of the curriculum used in the parent support group study. The focus groups revealed that parents held mixed feelings regarding the long-term outcomes for their children as they related to their sexuality and social relationships. Echoing the findings in previous research, parents in this study expressed concern about abuse and exploitation, as well as misinterpretation of their child's behavior and its legal implications. However, parents in this study also identified the need to address both the needs of other stakeholders within the community, in addition to the social impairments displayed by their children.

The second part of this study was based on a pilot parent sexuality education group, and aimed to address their learning needs, increase comfort and competence, and to create a sexuality curriculum that was founded on socialization and safety. Parent groups were conducted for eight weeks. A pretest/posttest design was used to look at changes in parent comfort ratings toward sexuality in relation to their child with autism. Parents completed The Comfort Ratings Questionnaire—Parent Version (Nichols, 2005), composed mostly of 5-point Likert questions prior to beginning the program. Upon completing the program, parents completed The End of Group Evaluation (Nichols, 2005). This questionnaire also asked about comfort level, as well as modifications in beliefs, knowledge, and goals about their child's future with regards to sexuality and relationships. The training sessions focused on sexuality issues for youth with autism, parents own experiences with sexuality education, parents' hopes and fears for their child with autism, goal setting, sexuality development, communication about sexuality, developing a sexuality education plan and multi-stakeholder teaching team, as well as teaching about specific topics (e.g., privacy, affection, boundaries). It was found that parents were able to set and achieve many goals, including learning to talk about critical issues with their child. Moreover, parental comfort level increased significantly from the start to the end of the training.

### Sexuality Case Studies

Included in the review are four research articles that used case study methodology to examine sexuality in individuals with autism. These studies examined either individuals' problematic sexual behaviors and/or sexual identities. In a case study conducted in the United States by Realmuto and Ruble (1999), questions were raised regarding the definition of deviant sexual behaviors, as well as the normalcy of specific sexual behaviors, as they relate to autism. This case looked specifically at a young adult male individual with a dual diagnosis of autism and schizophrenia who exhibited various inappropriate sexual behaviors, including public masturbation and sexual interest toward children. In this case, a variety of treatments were attempted to modify the inappropriate behaviors, including simple behavior programs, a sex education program, and various medical treatments. Of all of the treatments attempted, only the medical method via Leuprolide acetate depot injection was deemed effective at curbing the individual's sexually inappropriate behaviors. Other maladaptive behaviors persisted, including aggression and property destructions. The low rates of sexual behaviors were maintained over three years, even when the medication was tapered to a low level. The authors conclude that further research must be done to address sexual deviancy in individuals with developmental disabilities, including those with autism.

Of late, there has been an increase in research on the sexual identities of individuals with autism. A study by Galluci, Hackerman, and Schmidt (2005) looked at gender identity disorder in an adult male with Asperger syndrome. The person whom this case is about expressed a strong desire for gender reassignment surgery to become a woman. The authors of this study posit a potential relationship between gender identity disorder and obsessive compulsive disorder, a manifestation that may be more common in individuals on the autism spectrum. The study was descriptive, and as such, the authors propose potential solutions to the problem of gender identity disorder. They recommend medication aimed at treating obsessive compulsive disorder for gender identity disorder. They also speculate whether a gender-related dilemma may have helped the individual in this case to avoid potentially stressful socio-sexual contacts with others, thus serving as a personal barrier for the person in question.

More recent case studies, such as those reported by Tissot (2009) and Griffin-Shelley (2010), provide interesting findings as well. Tissot looked at multiple cases of young learners with autism attending a residential school in the south of England and examined their need for establishing a sexual identity. Case studies of individuals between 11 and 19 years of age were conducted via convenience sampling. The study looked at how the school in question used what it considered to be sexually based problems exhibited by students as a basis to provide a learning program that taught students how to establish what the researchers call a "sexual identity." The problem

behaviors included inappropriate or public masturbation, (non)consensual sexual contact with other students, distress at menstruation, sexual frustration related to inability to climax, and desire for a reciprocal same-sex intimate relationship with another student. In each case, a six-step program was followed to address the needs of the student. The steps included reviewing school policies and procedures, multistakeholder consultations, reviewing and implementing a sexual health education curriculum, sharing support strategies with all stakeholders, providing a referral process for ongoing support for students and teams, and implementing and reviewing the strategy used. The results for all but one student included a reduction of “problematic behaviors” (as defined by the researchers), as well as increased appropriate behaviors.

Griffin-Shelley (2010) also looked at problematic sexual behavior, conceptualized here as sexual addiction and sexual offending, for a 14-year-old male individual with Asperger syndrome. The individual had engaged in sexual acts with younger siblings and with younger male peers. As a result, he was sent to a residential treatment program for male sexually offending youth, where he remained for three years. The treatment used a five-step “Change, Accountability, Respect, Empathy, Support” (CARES) model. The individual remained at step 3, the empathy level, until his release from treatment at age 18. During his residential treatment, he was also given a number of medications, including Zoloft, Paxil, and Risperdal. Following his discharge, he continued treatment and therapy using models akin to the Ray et al. (2004) and Matich-Maroney, Boyle, and Crocker (2005) models. He was homeschooled until he graduated from high school and lived separately from his siblings. The individual continued to exhibit some problematic sexual behaviors and concerns remained regarding his danger of reoffending. The author suggests some strategies for dealing with individuals along the autism spectrum who also exhibit sexuality issues, including: addressing all contributing factors when planning intervention, including all stakeholders in intervention and providing appropriate training on sexuality and autism for these stakeholders, and using behavioral approaches.

## DISCUSSION

These studies vary greatly in their topics, their participants, and their methodology. In addition, most have been small in size, which limits the generalizations that can be inferred from them. As a result, the findings are difficult to compare. Nonetheless, there are some common threads that can be found among these varied studies. One commonality, above and beyond being about individuals with autism, is the consistent finding that individuals with autism are sexual and often have an interest in others. Another common thread is that, in many of the studies, sexuality is addressed from a

problem-based perspective. A third recurrent theme is the difficulty caregivers and individuals with autism have in translating theory into practice. It is around these three themes and through the use of a social-relational disability lens that we shall discuss the literature.

### Sex Matters

Indeed, what becomes apparent in all of these studies is that individuals with autism are sexual; they are interested in sexuality, have sexual needs, and oftentimes want to develop relationships with others. Moreover, individuals with autism display a wide variety of sexual interests and behaviors. In other words, sex matters. In Ousley and Mesibov (1991) and Konstantareas and Lunskey (1997), it was shown that individuals with autism are as interested in sex as individuals with intellectual disabilities but have less sexual experience. As a result, many experience sexual frustration (Hellemans et al., 2007; Ousley & Mesibov, 1991; Van Bourgondien et al., 1997). These studies also report that the individuals being researched demonstrate interest in having relationships with others (Hellemans et al., 2007; Van Bourgondien et al., 1997), putting to rest the myth that this population is uninterested in mutual sexual relationships. By applying Reindal's (2008) social-relational model of disability here, one can see that a societal barrier, notably sexual disregard, must be removed in order to allow for individuals with autism to be included within society to the fullest extent possible.

Parents and other caregivers are also acutely aware of the needs their children have in the area of sexuality, as was evidenced in studies conducted by Ruble and Dalrymple (1993), Stokes and Kaur (2005), Stokes et al. (2007), and Kalyva (2010). In fact, parents in one study were found to be increasingly concerned for their children with autism as they got older (Stokes & Kaur, 2005), and many caregivers acknowledge the need to teach socio-sexuality to their children but are unsure of how to go about it (Nichols & Blakeley-Smith, 2010; Ruble & Dalrymple, 1993; Van Bourgondien et al., 1997). Similarly, in Kalyva, 2010, only 12.5% of teachers felt confident they could provide appropriate socio-sexuality education to their students with autism. Application of the social relational model of disability in this instance exposes the needs related to the individuals' social and sexual impairments, as well parents' and other caregivers' needs regarding provision. Recognizing the needs of individuals with autism must go hand in hand with addressing the needs of parents and teachers through appropriate training and multi-stakeholder support, as was evidenced in Nichols and Blakeley (2010). By addressing these learning needs and thus removing these social barriers, an appropriate socio-sexuality education can then be provided in a systematic and proactive fashion (Nichols & Blakeley, 2010).

### Fear and Loathing: Problematic Sexuality or Sexuality as Problematic?

Striking in many of these studies is the discourse of fear and problematic sexuality that pervades the literature. This common theme manifests itself as sexual deviancy in Griffin-Shelley (2010) and the problem of sexual behavior definitions in Realmuto and Ruble (1999). In Galluci et al. (2005), the problem is defined as an individual's sexual gender identity issue but is translated into a problem of obsessive compulsive disorder. Finally, in Tissot (2009), the problem of sexuality is broached under the theme of sexual identity education but with every case stemming from a perceived sexual problem exhibited by the individual with autism. Thus, in all of these cases, sexuality is conceptualized as a problem behavior that is in need of being addressed.

Indeed, much research continues to pathologize sexuality and disempower the individual by focusing on the sexual behaviors as being issues of problems reported by a third party and in need of management. Such is the case in Hellemans et al.'s (2007) study which discusses the presence of *severe sexual problems* in 29% of individuals with autism. While some of these behaviors were indeed problematic (e.g., one individual had a paraphilia for young girls), other deemed "problematic autistic behaviors" included, for example, masturbation in the presence of others and attractions to certain individual particularities (e.g., facial features such as lips or eyes, a person's legs, breasts). While these particularities were expressed in a problematic manner, that is, in overtly blatant ways, the particularities themselves in many instances fell within the range of "normal" particularities found within the rest of the population (e.g., Love, 2004). Most people are attracted to particular attributes in a potential partner; these attributes may include certain physical or other sensorial features (e.g., a person's eyes, facial hair, how a person smells, their shape). These attractions are not problematic in and of themselves. What is problematic and in need of intervention is the deficit in social skills that allows for the inappropriate expression of these preferences, as is the deficit in discriminating public and private places to masturbate; this is where a social-relational model of disability can aptly be applied to address the needs of the individual with autism. By teaching the needed social skills (i.e., discrimination skills and the "hidden curriculum"), these "problematic autistic sexual behaviors" can be managed successfully. One can concurrently use the social-relational framework to help reframe the discourse away from the medicalization of behavior (and what has come to be known as "counterfeit deviance"; Hingsberger, Griffiths, & Quinsey, 1991), and move it toward the actual underlying deficit in social skills. This reframing can be done only through improved knowledge about autism, as well as increased awareness and training in use of evidence-based strategies for key stakeholders (e.g., policy makers, educators, parents, community partners). By reframing the problem from a peculiar autistic behavior to a skill deficit, we address both the social barrier and stigma associated with

this personal preference, as well as address the skill needed in the individual with autism.

Certainly, there may be times when behaviors cross the threshold of particular and become dangerous, as was the case in Griffin-Shelley (2010). In such instances, interventions appropriate to the situation should be used (see, e.g., Ray et al., 2004). Whether a sexual behavior is problematic depends on the circumstances in which it occurs. One way for stakeholders to determine an appropriate intervention for particular behavior is to ask the following hierarchy of questions:

1. Is it dangerous (to the individual or to others)?
2. Is it legal?
3. Is it moral or ethical?
4. Is it socially acceptable?

When answering these questions, one can see that there is a continuum of objectivity/subjectivity. At the top are questions that are more concretely answered. For example, if a person is using a sharp object to masturbate (engaging in a dangerous activity), then there is an obvious skill deficit that needs to be addressed. Similarly, if a person is exposing oneself in public (an illegal activity), there is also a skill that needs to be taught. Other behaviors are not so clear, for example, the frequency a person masturbates or views pornography (Griffin-Shelley, 2010). These particularities may not be dangerous or illegal, but their social and perhaps moral acceptability will depend on the person's personal, familial, community, and societal context. Griffin-Shelley (2010) discusses the importance of the appropriateness of the therapy provided to the individual and proposes that the nature of the impairment (Asperger syndrome in the case presented) and resulting needs (lack of social skills, anxiety, compulsive behavior, and lack of empathy) would point to interventions that address these needs. According to Griffin-Shelley, the offender intervention model utilized by the residential treatment program was inappropriate for the individual, as it did not directly address the needs of the person with autism. Through the social-relational lens of disability, the inappropriateness of the model reflects a societal barrier that prevents the individual from obtaining the accommodations needed for his particular impairment. Indeed, these examples highlight the importance of providing proactive socio-sexuality education that meets the emerging needs of individuals, as well as addressing the needs of society that may act as obstacles for individuals with autism.

Konstantareas and Lunsy (1997) found that the more individuals (regardless of group) knew about sexuality, the more negative were their views toward it. This finding again points toward the discourse of fear and protection that often accompanies any discussion about sex with populations that are deemed "vulnerable." Indeed, such populations are at an increased risk

of victimization and abuse (Mansell, Sobsey, & Moskal, 1998; Sobsey, 1994) and require access to a curriculum that targets these vulnerabilities (Gerhardt, 2006; Gordon, 1971; Kempton, 1975; Kreinin, 2001; Mitchell, 2010; Sobsey, 1994; Travers & Tincani, 2010). Nonetheless, the onus now rests upon society to provide not only the knowledge and skills required for this population to be better equipped against abuse but also to provide the information and abilities to be able to enjoy a healthy sexual identity. Indeed, striking a balance between the duty to protect from undue harm and the responsibility to provide access to full human rights, including sexuality rights (Herr, Gostin, & Hongju Koh, 2003; Kaeser, 1992; Lyden, 2007; Niederbuhl & Morris, 1993; Stavis, 1991) continues to be a difficult process (Kalyva, 2010). Erring on the side of caution can help to prevent exposing vulnerable persons to dangerous sexual situations; however, when such caution effectively impedes on their right to experience their full sexuality, more appropriate alternatives must be sought. As it currently stands, the sexual rights of individuals with autism are often curtailed under the guise of protection. In Van Bourgondien et al. (1997), for example, only four of the responding 14 residential programs allowed for any sexual contact beyond kissing. Thus, even if individuals did receive some form of socio-sexuality education, most were prevented from having any shared sexual experiences.

The flipside also appears in, for example, Realmuto and Ruble's case study (1999), where the sexuality of individuals with autism is questioned within a framework of deviancy. The individual in the case study was not representative of most individuals with autism, however, as the authors themselves state, such an individual represents the fear that exists in society towards persons they do not understand. While the authors used this example to explore the difficulties that entail when defining deviant versus inappropriate sexuality for persons with developmental disabilities, they effectively conflate the two by using an individual who clearly exhibited deviant sexual behaviors. Indeed the authors conclude their article by stating that "current societal trends to legislate and codify a variety of behaviors apparently responding to well-publicized cases of stalking, sexual harassment, and infection with deadly sexually transmitted diseases further contribute to parental and caregiver fears about sexual expression in individuals with autism" (pp. 126–127). Thus, while couched in a discourse of care, this case is used to reinforce the fears that exist within society and to further limit the sexual rights of individuals with autism.

Also concerning is Tissot's (2009) multiple case study, which again uses the discourse of care in a study that clearly shows examples of individuals' sexual rights being curtailed (Watson et al., 2002). Tissot argues for a need to develop what she terms a "sexual identity," which may have been more appropriately labeled "sexual health education." Indeed, the case studies all continue to address sexuality in individuals with autism from a problem-based perspective. Each of the cases stem from perceived problem behaviors,

including public masturbation and other sexualized behaviors. While addressing these needs is certainly important and valid, they do not address the “sexual identities” of the individuals in question. Case in point, one of the instances was specifically about the desire of two students to establish a same-sex relationship. Both students were 19 years old, enjoyed spending time together, and appeared mutually consensual. However, because the parents of one of the students were against a homosexual relationship, and because the school in question did not allow for sexual contact between students, these two individuals were prohibited from establishing such a relationship. Even upon graduation and adult placement, the students were kept separate. This is a clear example of how the establishment of a sexual identity here is simply a misnomer. It is in fact simply the negation of sexuality in both individuals. One can acknowledge the tension that exists between the right to sexual expression and the duty to protect against undue harm, especially in a residential school where vulnerable individuals are under the care of professionals who are bound by legislation regarding their responsibilities to protect against sexual exploitation. Nonetheless, there is a responsibility for all stakeholders to recognize the right of individuals to be sexual, and this includes the dignity to be sexual with other consenting adults. Through the social-relational lens of disability, one can see that it is a matter of societal barriers, not simply personal impairment, that prevent access to the individuals’ full sexuality rights. The views of the parents, staff, and researchers, as well as the residential program’s policies, all combine to effectively negate the individuals’ sexuality. As has been stated in Brown and Pirtle (2008), Swango-Wilson, Watson et al. (2002), Wolfe (1997), and elsewhere, the attitudes and personal beliefs of others impact on the sexuality rights of individuals with disabilities. These attitudes and beliefs often act as societal barriers and must therefore be addressed forthrightly.

The same theme is repeated in Galluci et al. (2005), where the views of the authors impact on the sexuality of the individual with autism. The authors in this case study fail to acknowledge the legitimacy of the person’s desire for gender reassignment. Rather, they simply propose a means of managing the situation via a pharmacological solution. They associate the person’s dissatisfaction with their gender as being a symptom of obsessive compulsive disorder rather than as its own issue. As a result, the authors may in effect be proposing a solution to an unrelated problem rather than addressing the individual’s actual needs. From a social-relational perspective of disability, we can see that the needs of the individual cannot be met until the social obstacles, the views of the authors, are effectively addressed. Moreover, the authors go on to speculate that the individual’s gender issues may have been partly contrived to avoid contact with others. Again, while this is merely proposed as speculation for further inquiry, it works to effectively negate the individual’s expressed needs relating to his sexuality rather than provide any viable solutions to his needs. Such questioning and negation in

other circumstances could be quickly refuted, but because of the social and communication deficits experienced by many individuals with autism, it may prove impossible to advocate effectively for oneself. Even if this hypothesis were true, the effective solution according to a social-relational perspective of disability would not be a pharmacological intervention, but rather access to appropriate socio-sexuality education. This education could address the sensory and social issues (e.g., Hénault, 2006) that may have precipitated the individual's intimacy issues, as well as address his communicative deficits and thus allow him to better advocate for his needs.

### Translating Theory into Practice

A third common theme found in many of the studies was the difficulty with which individuals with autism used the information that they received in their everyday lives. In Konstantareas and Lunsy (1997), for example, individuals were aware of sexual terminology but did not display a complex understanding of these terms. In Griffin-Shelley (2010), the individual could identify the components of the curriculum being taught, but struggled with the application of the different concepts. A similar finding was noted by Ruble and Dalrymple (1993), where individuals manifested a variety of sexually inappropriate behaviors, regardless of verbal abilities, as was the case in Stokes and Kaur (2005), where knowledge and behaviors were inconsistent. Hellemans et al. (2007) also reported that individuals showed a gap in putting knowledge into practice, and exhibited socially and sexually inappropriate behaviors toward others. Without a doubt, a common problem with this population is their difficulty in identifying, understanding, and managing complex behaviors (e.g., Attwood, 2004; Hénault, 2006). This was certainly demonstrated in Stokes et al. (2007), which found that individuals with autism displayed more socially and sexually inappropriate behaviors, persisted in their behaviors for longer periods of time and despite negative responses from the recipients, than did their nondisabled counterparts. Similarly, in Ruble and Dalrymple (1993), the transferral of knowledge into practice was inconsistent since parents of children with autism confirmed providing some sexuality education to their children, while they also reported the presence of inappropriate sexual behaviors by these same children.

People with autism display skill deficits in the social and communication domains. They are often also excluded from typical and consistent interactions with their peers, or if they are in contact with peers, interactions are stifled because of constant adult surveillance (Watson, Shakespeare, Cunningham-Burley, & Barnes, 1999). This was demonstrated in Stokes et al. (2007), where children with autism had not acquired social and sexual knowledge from their peers. The socio-sexual mores that are learned naturally and incidentally for others must be taught explicitly to individuals with

autism. A social-relational approach to disability helps us to identify the nature of the barriers that exist in this situation. An education that explicitly addresses sexuality from a social perspective can address both of the social and communication deficits and can explicitly teach the “hidden curriculum.” However, these strategies will be insufficient to change their long-term outcomes if societal barriers are not removed. In addition to addressing the impairment, increased opportunities for interactions with peers in natural settings must be provided (Nichols & Blakeley-Smith, 2010). This can be accomplished by increasing the inclusiveness of schools, community settings, and society as a whole. This point is emphasized by a parent in Nichols and Blakely-Smith (2010), who states that there is a need for “training for other people to more understanding, sensitive and appropriate regarding our children’s needs” (p. 80). Addressing both needs and barriers are necessary if individuals with autism to be successful at navigating the socio-sexual world.

### MOVING FORWARD

What is clear at this point is that there exists research that debunks the myth that individuals with autism are either asexual or hypersexual. Individuals with autism are sexual, have social and sexual needs, and want to experience social and sexual relationships with others. The research has also shown us that individuals with autism continue to have their sexuality rights denied. While individuals with autism do present with developmental delays in many areas, their physical development is not equally delayed. As a result, they manifest a variety of problematic behaviors, many of which are associated with deficits related to communication and social skills. Such behaviors cause many individuals to be marginalized and socially excluded, while other behaviors can involve legal ramifications (e.g., Griffin-Shelley, 2010; Hellemans et al., 2007; Stokes et al., 2007). Many researchers argue that there is a demonstrated need for targeted socio-sexuality education and that providing such an education can help individuals with autism to modulate their behavior and improve their quality of life (Hatton & Tector, 2010; Konstantareas & Lunsky, 1998; Stokes & Kaur, 2005). Stokes et al. go so far as to recommend that “intensive socio-sexual interventions are required to improve social interaction skills and provide experiences so that [individuals with autism] are able to develop better social and romantic functioning without encountering serious problems” (2007, p. 1980). Certainly, the provision of an adapted socio-sexuality education can help to address the needs germane to this population. Kalyva, 2010, goes so far as to say that “the question is not if individuals with ASD will receive sexuality education, but how it will be offered” (p. 436).

To simply address the socio-sexual needs exhibited by individuals with autism is no longer sufficient. Undeniably, an ongoing fundamental problem

remains in the perceptions and attitudes of society towards the sexuality of individuals with developmental disabilities. If these negative attitudes and perceptions are not addressed and transformed, then all strides made in addressing the needs of individuals with autism are meaningless, as they will not result in any meaningful changes within society. Indeed, much of the research conducted thus far, while useful in demonstrating the need for socio-sexuality education for this population, has also managed to perpetuate the stigma of sexuality as a problem in need of management. A good deal of prior research in this field has failed to address sexuality issues for individuals with autism as a problem of social exclusion. More research is needed that adopts Reindal's (2008) social-relational model of disability. It does seem a sea change is upon us, what with research from the likes of Griffin-Shelley (2010), Kalyva (2010), Nichols-Blakely (2010), and other work by, for example, Hatton and Tector (2010) or Travers and Tincani (2010). Their research acknowledges and addresses the real skill deficits which reside within individuals with autism while also exposing and addressing the social barriers that prevent the provision of socio-sexuality education to this population. The adoption of such a methodology allows for a holistic approach to the individual with autism as a member within a community, and as such, is a truly socially-inclusive model. More research focused on identifying evidence-based means of addressing the societal barriers that prevent the provision of socio-sexuality education is needed. Such research can help improve the long-term social and sexual outcomes for individuals with autism.

## NOTES

1. Unless otherwise noted, I shall be using the term "autism" as inclusively meaning "autism spectrum disorder," "Asperger syndrome," and "pervasive developmental disorder—not otherwise specified." I will not be using the acronyms ASD, AS, or PDD-NOS because of my belief that using acronyms as labels inevitably encourages the abstraction of both the individual and the impairment (how often has one heard "He/she is OCD" or "He/she is ADHD" to refer to an individual with an obsessive compulsive disorder (OCD) or attention deficit hyperactivity disorder (ADHD). In these all-too-common examples, the impairments no longer provide information about the individual but rather *define* the individual (the individual no longer "has" but rather "is" an impairment). This presents the dangerous possibility of creating a slippery-slope where people are no longer seen as such, and where dehumanizing statements can be made on their behalf.

2. The term "intellectual disability" is used here according to the definition set out in Schalock, Borthwick-Duffy, Bradley, Buntinx, Coulter, Ellis, et al. (2010).

3. I have opted to use the term "sexuality" rather than "sex" because the latter term has come to be associated with a narrower definition of education on the subject of sexuality. Sexuality education encompasses more than learning about anatomy, physiology, reproduction, and sexually transmitted infections, as is often assumed when using the term "sex education." "Sexuality education" addresses more aspects of sexuality, such as sexual health, sexual behavior, society and culture, and so forth (SIECUS,

2004). The addition of the term "socio" is to emphasize the social aspects of sexuality, components such as personal skills and healthy relationships. (SIECUS, 2004). These topics are essential for students with autism, as they often have deficits in the areas communication and social skills. If not explicitly stated, these components are at risk of being left out of the curriculum employed with students who have autism.

4. This time period was chosen for two reasons. Until relatively recently, distinctions were not made between categories of intellectual and developmental disabilities, including autism. As a result, very little research has been conducted specifically on the sexuality and/or socio-sexuality education of individuals with autism specifically. Since there are particularities to sexuality and socio-sexuality education specific to autism, more general research studies that did not specify ‘autism’ were excluded. Likewise, it was not until 1987 that a definition of ‘autistic disorder’ similar to the one used today was added to the Diagnostic and Statistical Manual of Mental Disorders (DSM III-Revised). Prior to 1987, autism was categorized as “Infantile Autism” (DSM III, 1980) and “Schizophrenia: Childhood Type” (DSM I, 1952; DSM II, 1968) (APA, 1952, 1968, 1980, 1987; Grinker, 2007).

## REFERENCES

- Alpern, G. D., Boll, T. J., & Shearer, M. S. (1984). *Developmental profile II*. Los Angeles, CA: Western Psychological Services.
- Aman, M. G., & Singh, N. N. (1986). *Aberrant behavior checklist manual*. East Aurora, NY: Slosson.
- American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders*. Washington, DC: Author.
- American Psychiatric Association. (1968). *Diagnostic and statistical manual of mental disorders* (2nd ed.). Washington, DC: Author.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: Author.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed., rev.). Washington, DC: Author.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., rev.). Washington, DC: Author.
- Attwood, T. (2004). *Exploring feelings: Cognitive behavior therapy to manage anger and anxiety*. Arlington, TX: Future Horizons.
- Aylott, J. (2000). Autism in adulthood: The concepts of identity and difference [Electronic version]. *British Journal of Nursing*, 9(13), 851–858.
- Bacharach, L. L. (1985). Deinstitutionalization: The meaning of the least restrictive environment. In R. H. Bruininks & K. C. Lakin (Eds.), *Living and learning in the least restrictive environment* (pp. 23–36). Baltimore, MD: Paul H. Brookes Publishing.
- Barnhill, G. P. (2007). Outcomes in adults with Asperger syndrome [Electronic version]. *Focus on Autism and Other Developmental Disabilities*, 22(2), 116–126.
- Baron-Cohen, S. (2001). Theory of mind in normal development and autism. *Prisme*, 34, 174–183.
- Brown, R. D., & Pirtle, T. (2008). Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: Examining beliefs using a Q-methodology approach [Electronic version]. *Sex Education*, 8(1), 59–75.
- Centers for Disease Control and Prevention. (2010). *Autism Information Center: Facts about ASDs*. Retrieved from <http://www.cdc.gov/ncbddd/autism/facts.html>
- Champagne, M. P., & Walker-Hirsch, L. W. (1993). *Circles I: Intimacy and relationships* (rev. ed.). Santa Barbara, CA: James Stanfield Publishing.
- Chin, H. Y., & Bernard-Opitz, V. (2000). Teaching conversational skills to children with autism: Effect on the development of a theory of mind. *Journal of Autism and Developmental Disorders*, 30(6), 569–583.

- Craft, A. (Ed.). (1994). *Practice issues in sexuality and learning disabilities*. London, England: Routledge.
- Di Giulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *The Canadian Journal of Human Sexuality*, 12(1), 53–68.
- Durocher, L., & Fortier, M. (1999). *Programme d'éducation sexuelle*. Montréal, Quebec, Canada: Les Centres Jeunesse de Montréal et la Régie régionale de la santé et des services sociaux, Direction de la santé publique.
- Galluci, G., Hackerman, F., & Schmidt, C. W. (2005). Gender identity disorder in an adult male with Asperger's syndrome [Electronic version]. *Sexuality and Disability*, 23(1), 35–40.
- Gardner, J. F., & Chapman, M. S. (1990). *Program issues in developmental disabilities: A guide to effective habilitation and active treatment* (2nd ed.). Baltimore, MD: Paul H. Brookes Publishing.
- Gerhardt, P. (2006, November–December). Sexuality instruction and autism spectrum disorders. *Autism & Asperger's Digest Magazine*, 44–46.
- Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in persons with autism: Implications for research and clinical care. *Journal of Autism and Developmental Disorders*, 32(4), 299–305.
- Gordon, S. (1971). Missing in special education: Sex. *Journal of Special Education*, 5, 351–354.
- Gougeon, N. A. (2009). Sexuality education for students with intellectual disabilities, a critical pedagogical approach: Outing the ignored curriculum. *Sex Education*, 3(9), 277–291.
- Gray, C. A. (1994). *Comic strip conversations*. Arlington, VA: Future Horizons.
- Gray, C. A. (2002). *My social stories book*. London, England: Jessica Kingsley Publishers.
- Gray, S., Ruble, L., & Dalrymple, N. (2000). *Autism and sexuality: A guide for instruction*. Bloomington: Autism Society of Indiana.
- Greenspan, S. (2002). A sex police for adults with “mental retardation”? Comment on Spiecker and Steutel [Electronic version]. *Journal of Moral Education*, 31(2), 171–179.
- Griffin-Shelley, E. (2010). An Asperger's adolescent sex addict, sex offender: A case study [Electronic version]. *Sexual Addiction & Compulsivity*, 17(1), 46–64.
- Griffiths, D. (2003). Sexuality and people who have developmental disabilities: From myth to emerging practices. In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (2nd ed., pp. 677–690). Toronto, Canada: Ontario Association on Developmental Disabilities.
- Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. Cambridge, MA: Basic Books.
- Haracopos, D., & Pedersen, L. (1992). *Sexuality and Autism: A nationwide survey in Denmark*. Unpublished manuscript.
- Hatton, S., & Tector, A. (2010). Sexuality and relationship education for young people with autistic spectrum disorder: Curriculum change and staff support [Electronic version]. *British Journal of Special Education*, 37(2), 69–76.
- Haugaard, J. J., & Seri, L. G. (2004). Stalking and other forms of intrusive contact among adolescents and young adults from the perspective of the person

- initiating the intrusive contact. *Criminal Justice and Behavior*, 31, 37–54.
- Hellemans, H., Colson, K., Verbraeken, C., Vermeiren, R., & Deboutte, D. (2007). Sexual behavior in high-functioning male adolescents and young adults with Autism Spectrum Disorder [Electronic version]. *Journal of Autism and Developmental Disorders*, 37(2), 260–269.
- Hénault, I. (2006). *Sexualité et syndrome d'Asperger*. Brussels, Belgium: De boeck.
- Herr, S., Gostin, L., & Hongju Koh, H. (Eds.). (2003). *The human rights of persons with intellectual disabilities: Different but equal*. New York, NY: Oxford University Press.
- Heward, W. L. (1987). Basic concepts. In J. O. Cooper, T. E. Heron, & W. L. Heward (Eds.), *Applied behavior analysis* (pp. 16–34). Upper Saddle River, NJ: Prentice-Hall.
- Hingsburger, D., Griffiths, D., & Quinsey, V. (1991). Detecting counterfeit deviance. *The Habilitative Mental Healthcare Newsletter*, 10(9), 51–54.
- Howlin, P. (2004). *Autism and Asperger syndrome: Preparing for adulthood* (2nd ed.). New York, NY: Routledge.
- Kaaser, F. (1992). Can people with severe mental retardation consent to mutual sex? [Electronic version]. *Sexuality and Disability*, 10(1), 33–42.
- Kalyva, E. (2010). Teachers' perspectives of the sexuality of children with autism spectrum disorders [Electronic version]. *Research in Autism Spectrum Disorders*, 4, 433–437.
- Kempton, W. (1975). *A teacher's guide to sex education for persons with learning disabilities*. North Scituate, MA: Duxbury Press.
- Kempton, W. (1993). *Socialization and sexuality: A comprehensive guide*. Santa Barbara, CA: James Stanfield Company.
- Koller, R. (2000). Sexuality and adolescents with autism [Electronic version]. *Sexuality and Disability*, 18(2), 125–135.
- Konstantareas, M. M., & Lunsky, Y. (1997). Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay [Electronic version]. *Journal of Autism and Developmental Disorders*, 27(4), 397–413.
- Kreinin, T. (2001). Sexuality education for the disabled is priority at home and school. *SIECUS Report*, 29(3), 3.
- La Malfa, G., Lassi, S., Bertelli, M., Salvini, R., & Placidi, G. F. (2004). Autism and intellectual disability: A study of prevalence on a sample of the Italian population [Electronic version]. *Journal of Intellectual Disability Research*, 48(3), 262–267.
- Lavoie, R. (2005). *It's so much work to be your friend: Helping child with learning disabilities find social success*. New York, NY: Simon & Schuster.
- Lawson, W. (2005). *Sex, sexuality and the autism spectrum*. Philadelphia, PA: Jessica Kingsley Publishers.
- Lemay, M. (1996). *La sexo trousse*. Maniwaki, Quebec, Canada: Pavillon du Parc.
- Love, B. (2004). United States: Significant unconventional sexual behaviors. D: Paraphilias and unusual sexual practices. In R. T. Francoeur & R. J. Noonan (Eds.), *The continuum complete international encyclopedia of sexuality* (pp. 1245–1250). New York, NY: Continuum.

- Lyden, M. (2007). Assessment of sexual consent capacity [Electronic version]. *Sexuality and Disability*, 25(1), 3–20.
- Mansell, S., Sobsey, D., & Moskal, R. (1998). Clinical findings among sexually abused children with and without developmental disabilities. *Mental Retardation*, 36(1), 12–22.
- Matich-Maroney, J., Boyle, P. S., & Crocker, M. M. (2005). The psychosexual assessment and treatment continuum: A tool for conceptualizing the range of sexuality-related issues and support needs of individuals with developmental disabilities. *Mental Health Aspects of Developmental Disabilities*, 8, 1–14.
- McCann, J. T. (2004). A descriptive study of child and adolescent obsessional followers. *Journal of Forensic Science*, 45, 195–199.
- Meister, C., Norlock, D., Honeyman, S., & Pierce, K. (1994). Sexuality and autism: A parenting skills enhancement group. *Canadian Journal of Human Sexuality*, 3(3), 283–289.
- Mitchell, L. (2010, August 4). *Bringing the birds & bees down to earth: Sexuality education for individuals with autism*. Paper presented at the 2010 Penn State National Autism Conference. State College, Pennsylvania. Retrieved from <http://www.outreach.psu.edu/programs/autism/files/48mitchell.pdf>
- Monat-Haller, R. K. (1992). *Understanding & expressing sexuality: Responsible choices for individuals with developmental disabilities*. Baltimore, MD: Paul. H. Brookes Publishing.
- Myles, B. S., & Simpson, R. L. (2001). Understanding the hidden curriculum: An essential social skill for children and youth with Asperger syndrome. *Intervention in School and Clinic*, 36(5), 279–286.
- Nichols, S., & Blakeley-Smith, A. (2010). “I’m not sure we’re ready for this . . .”: Working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders [Electronic version]. *Social Work in Mental Health*, 8(1), 72–91.
- Niederbuhl, J. M., & Morris, C. D. (1993). Sexual knowledge and the capability of persons with dual diagnoses to consent to sexual contact. *Sexuality and Disability*, 11(4), 295–307.
- Norwich, B. (2002). Education, inclusion and individual differences: Recognizing and resolving dilemmas. *British Journal of Educational Studies*, 50(4), 482–502.
- Ousley, O. Y., & Mesibov, G. B. (1991). Sexual attitudes and knowledge of high-functioning adolescents and adults with Autism. *Journal of Autism and Developmental Disorders*, 21(4), 471–481.
- Ozonoff, S., Garcia, N., Clark, E., & Lainhart, J. E. (2005). MMPI-2 personality profiles of high-functioning adults with autism spectrum disorders. *Assessment*, 12(1), 86–95.
- Plaute, W., Westling, D., & Cizek, B. (2002). Sexuality education for adults with cognitive disabilities in Austria: Surveys of attitudes and the development of a model program [Electronic version]. *Research and Practice for Persons with Severe Disabilities*, 27(1), 58–68.
- Radford, J. P., & Park, D. C. (2003). Historical overview of developmental disabilities in Ontario. In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (2nd ed., pp. 3–18). Toronto, Canada: Ontario Association on Developmental Disabilities.

- Ray, F., Marks, C., & Bray-Garretson, H. (2004). Challenges to treating adolescents with Asperger's syndrome who are sexually abusive [Electronic version]. *Sexual Addiction & Compulsivity*, 11(4), 265–285.
- Realmuto, G. M., & Ruble, L. A. (1999). Sexual behaviors in autism: Problems of definition and management [Electronic version]. *Journal of Autism and Developmental Disorders*, 29(2), 121–127.
- Reindal, S. M. (2008). A social-relational model of disability: A theoretical framework for special needs education? [Electronic version]. *European Journal of Special Needs Education*, 23(2), 135–146.
- Rogers, S. J. (2000). Interventions that facilitate socialization in children with autism [Electronic version]. *Journal of Autism and Developmental Disorders*, 30(5), 399–409.
- Ruble, L. A., & Dalrymple, N. J. (1993). Social/sexual awareness of persons with autism: A parental perspective. *Archives of Sexual Behavior*, 22(3), 229–240.
- Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Ellis, M. P., . . . Yeager, M. H. (2010). *Intellectual disability: Definition, classification, and systems of support* (11th ed.). Washington, DC: AAIDD.
- Schopler, E. (1997). Implementation of TEACCH philosophy. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 767–795). New York, NY: John Wiley.
- Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *The sexual politics of disability, untold desires*. London, England: Cassell.
- SIECUS National Guidelines Task Force. (2004). *Guidelines for comprehensive sexuality education* (3rd ed.). New York, NY: Fulton Press.
- Sobsey, D. (1994). Sexual abuse of individuals with intellectual disability. In A. Craft (Ed.), *Practice issues in sexuality and learning disabilities* (pp. 93–115). New York, NY: Routledge.
- Spitzberg, B. H., & Cupach, W. R. (2003). What mad pursuit? Obsessive relational intrusion and stalking related phenomena. *Aggression and Violent Behavior*, 8, 345–375.
- Stavis, P. F. (1991). Harmonizing the right to sexual expression and the right to protection from harm for persons with mental disability [Electronic version]. *Sexuality and Disability*, 9(2), 131–141.
- Stokes, M. A., & Kaur, A. (2005). High-functioning autism and sexuality: A parental perspective [Electronic version]. *Autism*, 9(3), 266–289.
- Stokes, M. A., Newton, N., & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder [Electronic version]. *Journal of Autism and Developmental Disorders*, 37, 1969–1986.
- Sullivan, A., & Caterino, L. C. (2008). Addressing the sexuality and sex education of individuals with autism spectrum disorder [Electronic version]. *Education and Treatment of Children*, 31(3), 381–394.
- Swango-Wilson, A. (2008). Caregiver perception of sexual behaviors of individuals with intellectual disabilities [Electronic version]. *Sexuality and Disability*, 26(3), 167–174.

- Tarnai, B. (2006). Review of effective interventions for socially inappropriate masturbation in persons with cognitive disabilities [Electronic version]. *Sexuality & Disability, 24*, 151–168.
- Tarnai, B., & Wolfe, P. S. (2008). Social stories for sexuality education for persons with autism/pervasive developmental disorder [Electronic version]. *Sexuality and Disability, 26*, 29–36.
- Tissot, C. (2009). Establishing a sexual identity—case studies of learners with autism and learning difficulties [Electronic version]. *Autism, 13*(6), 551–566.
- Travers, J., & Tincani, M. (2010). Sexuality education for individuals with autism spectrum disorders: Critical issues and decision making guidelines [Electronic version]. *Education and Training in Autism and Developmental Disabilities, 45*(2), 284–293.
- Tremblay, M., & Pigeon, C. (2004). De la reconnaissance du droit à l'élargissement de l'espace démocratique pour les "personnes présentant une déficience intellectuelle" [Electronic version]. *Revue Francophone de la Déficience Intellectuelle, 15*(1), 133–141.
- Van Bourgondien, M. E., Reichle, N. C., & Palmer, A. (1997). Sexual behavior in adults with autism [Electronic version]. *Journal of Autism and Developmental Disorders, 27*(2), 113–125.
- Watson, N., Shakespeare, T., Cunningham-Burley, S., & Barnes, C. (1999). *Life as a disabled child: A qualitative study of young people's experiences and perspectives, final report*. University of Leeds, Disability Research Unit. Leeds, UK: ESRC Research Programme.
- Watson, S., Venema, T., Molloy, W., & Reich, M. (2002). Sexual rights and individuals who have a developmental disability. In D. Griffiths, D. Richards, P. Federoff, & S. Watson (Eds.), *Ethical dilemmas: Sexuality and developmental disability* (pp. 19–52). Kingston, NY: NADD Press.
- Winter, E. C. (2003). Developmental disabilities in Ontario's schools. In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (2nd ed., pp. 583–602). Toronto, Canada: Ontario Association on Developmental Disabilities.
- Wish, J. R., McCombs, K. F., & Edmonson, B. (1980). *The socio-sexual knowledge and attitudes test*. Wood Dale, IL: Stoelting Co.
- Wolfe, P. S. (1997). The influence of personal values on issues of sexuality and disability. *Sexuality and Disability, 15*(2), 69–90.
- Wolfe, P. S., & Blanchett, W. J. (2003). Sex education for students with disabilities: An evaluation guide [Electronic version]. *Teaching Exceptional Children, 36*(1), 46–51.
- Wolfe, P. S., Condo, B., & Hardaway, E. (2009). Sociosexuality education for persons with autism spectrum disorders using principles of applied behavior analysis [Electronic version]. *Teaching Exceptional Children, 42*(1), 50–61.
- Wolfensberger, W. (1977). *The principle of normalization in human services*. Toronto, Canada: National Institute of Mental Retardation.
- Wrobel, M. (2003). *Taking care of myself—a healthy hygiene, puberty and personal curriculum for young people with autism*. Arlington, TX: Future Horizon.

## Appendix B: Summary of Sexuality Studies about Individuals with Autism Detailed in Literature Review

Table B1

Summary of Sexuality Studies about Individuals with Autism Detailed in Literature Review<sup>13</sup>

Study	Sample Size and Description	Research Methodology	Major Findings
<b>Ousley and Mesibov (1991)</b>	<i>Self-Perceptions</i> 41 individuals: 21 with high-functioning autism (11 males, mean IQ = 84.4; 10 females, mean IQ = 73.9) 20 with a mild to moderate intellectual disability (10 males, mean IQ = 56.9; 10 females, mean IQ = 54.6)	Questionnaire and structured interview administered by examiner (orally) and completed verbally	- Similar levels of interest and knowledge in sexuality across both groups - Significantly less sexual experiences (personal or shared) for individuals with autism
<b>Konstantareas and Lunsky (1997)</b>	31 individuals: 15 with autism (9 males; 6 females) 16 with an intellectual disability (8 males; 8 females)	Questionnaire and structured interview (with visual aids) administered by examiner (orally) and completed verbally/with gestures	- Similar levels of interest in sexuality across both groups - Increased sexual knowledge related to increased negative attitude towards sexuality - Lack of complex understanding relating to sexuality - Variety of sexual experiences and behaviours reported
<b>Hatton and Tector (2010)</b>	12 individuals with high-functioning autism	Questionnaire (12) and semi-structured interview (4) (in person or via e-mail)	Literature review: - Useful resources exist; lack of relationship-specific tools Surveys: - Sexuality education received lacked

<sup>13</sup> Adapted from Gougeon (2010).

Study	Sample Size and Description	Research Methodology	Major Findings
<b>Mehzabin and Stokes (2011)</b>	60 individuals: 21 with high-functioning autism (12 males; 9 females) 39 neurotypical individuals (15 males; 24 females)	Self-administered questionnaire (paper or online)	relationship skill content Interviews: - Varied feelings towards own sexuality and relationships reported - Retrospective desire for better self-knowledge/understanding of autism and its impact on socio-sexual lives
<b>Gilmour et al. (2012)</b>	364 individuals: 82 with high-functioning autism (17 males; 55 females) 282 neurotypical individuals (102 males; 180 females)	Self-administered online questionnaire	- Lower levels of sexual experience, social, and sexual behaviours for individuals with autism - Similar self-reported privacy-seeking behaviours - Higher concern about future in individuals with autism - Interest in sex and sexual behaviour of individuals with autism similar to neurotypical population - Similar levels of theoretical sexuality knowledge - Higher rates of asexuality (both genders) and lower rates of heterosexuality (females) in individuals with autism
<b>Ruble and Dalrymple (1993)</b>	<i>Perceptions of Others</i> 100 caregivers reporting on 100 individuals with autism (individuals with autism consisted of 68 males and 32 females)	Self-administered written questionnaire completed by parent or legal guardian	- Presence of sexual behaviours (appropriate and inappropriate) across sample - Verbal skills positively correlated to sexual knowledge and understanding - Parental concern regarding

Study	Sample Size and Description	Research Methodology	Major Findings
<b>Van Bourgondien et al. (1997)</b>	Caregivers reporting on 89 individuals with autism (individuals with autism consisted of 72 males and 17 females)	Self-administered written questionnaire completed by group home staff	<p data-bbox="1367 272 1873 410">misinterpretation of behaviours, teaching sex education, potential negative consequences related to sexuality</p> <ul data-bbox="1367 456 1873 667" style="list-style-type: none"> <li>- Presence of sexual behaviours in 74% of sample</li> <li>- Presence of person-directed sexual behaviours in 34% of sample</li> <li>- Limited sexual expression for most individuals with autism</li> </ul>
<b>Stokes and Kaur (2005)</b>	74 parents reporting on 23 children with high-functioning autism or Asperger syndrome (17 male; 6 female); and 50 neurotypical children (33 males; 17 females)	Self-administered written questionnaire completed by parent or legal guardian	<ul data-bbox="1367 711 1873 1182" style="list-style-type: none"> <li>- Compared to neurotypical children, children with autism displayed more socially inappropriate behaviours, demonstrated less privacy skills, knew less about sex education, and had parents who were more concerned about their long-term outcomes</li> <li>- Parental concern increased as children with autism aged; concern decreased as neurotypical children aged</li> <li>- A developmental lag appears to be present in children with autism</li> </ul>
<b>Stokes et al. (2007)</b>	63 parents reporting on 25 individuals with high-functioning autism (16 males; 9 females); and 38 neurotypical individuals (32 males; 6 females)	Self-administered written questionnaire completed by parent or legal guardian	<ul data-bbox="1367 1222 1873 1401" style="list-style-type: none"> <li>- Sources of information on social, romantic, and sexuality skills less likely to come from peers for individuals with autism</li> <li>- Individuals with autism had lower</li> </ul>

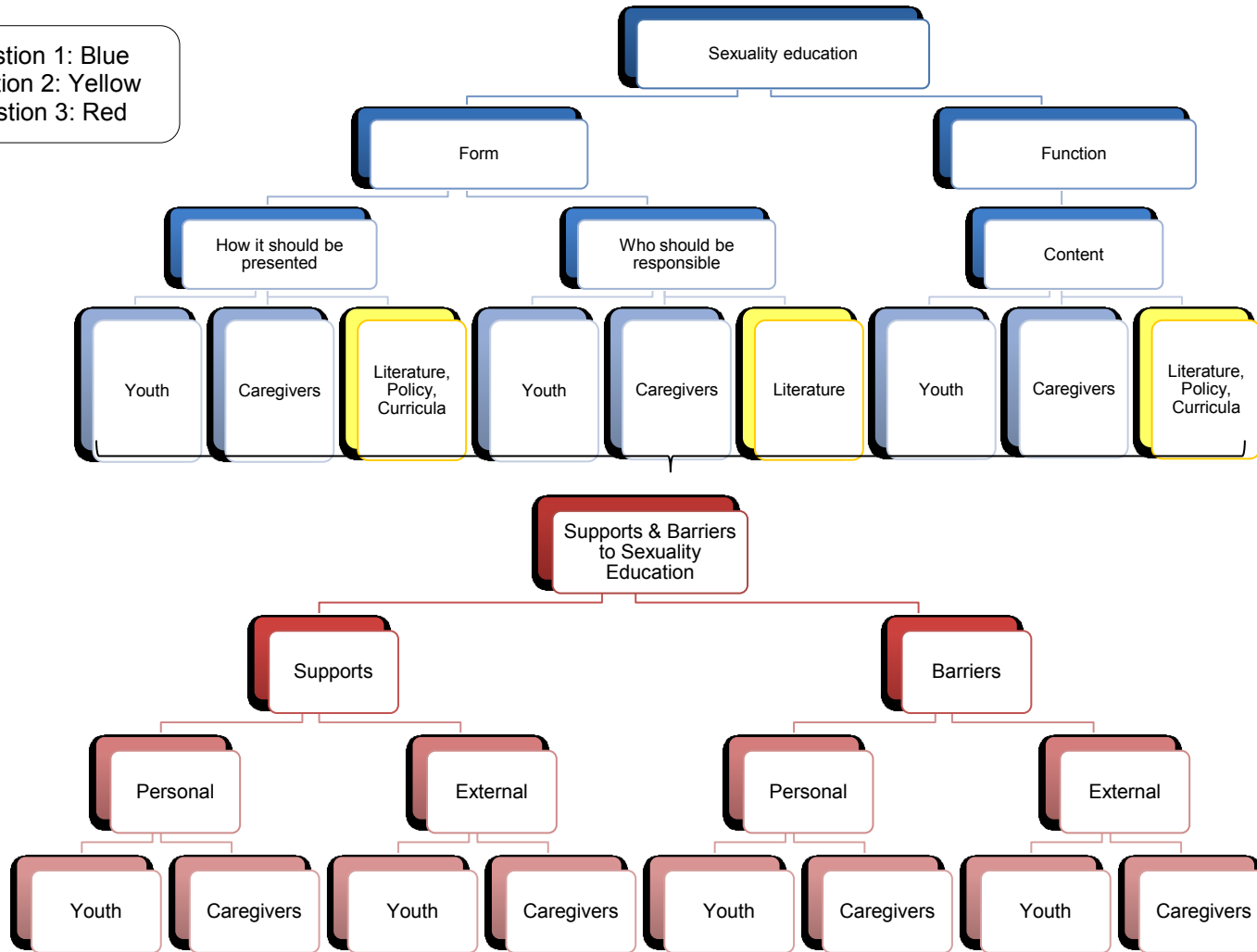
Study	Sample Size and Description	Research Methodology	Major Findings
<b>Hellemans et al. (2007)</b>	17 caregivers reporting on 24 male individuals along the autism spectrum: (14 autism; 6 pervasive developmental disorder – not otherwise specified; 4 Asperger syndrome)	Semi-structured interview with caregivers	<p>levels of social functioning than neurotypical peers</p> <ul style="list-style-type: none"> <li>- Individuals with autism exhibited more atypical and inappropriate social and romantic behaviours, exhibited behaviours towards more inappropriate targets, and for longer periods of time</li> <li>- High rates of interest in sexuality (96%)</li> <li>- Discrepancy between theoretical knowledge and its application</li> <li>- Variety of sexual behaviours present</li> <li>- Many displayed an interest in sexual relationships with others (42%)</li> </ul>
<b>Nichols and Blakeley-Smith (2009)</b>	Focus group participants: 21 parents (1 male; 20 females) of children with autism (13 males; 8 females) Parent education groups: Parents of 10 children with autism (5 males; 5 females)	Focus groups with parents; pretest/posttest effectiveness evaluation of sexuality education curriculum	<p>Focus groups:</p> <ul style="list-style-type: none"> <li>- Main themes included: finding meaning of “healthy sexuality” for individuals with autism; desire for relationships; significance of social impairments; exploitation prevention; multi-stakeholder support; parent resources</li> </ul> <p>Parent education groups:</p> <ul style="list-style-type: none"> <li>- Many parental goals met</li> <li>- Increased comfort in all areas</li> </ul>
<b>Kalyva (2010)</b>	56 teachers reporting on 76 children: 56 children with low functioning autism (38 males; 18 females);	Self-administered written questionnaire	<ul style="list-style-type: none"> <li>- Appropriate social and privacy behaviours, as well as knowledge of privacy and sexuality all positively</li> </ul>

Study	Sample Size and Description	Research Methodology	Major Findings
<b>Ballan (2012)</b>	20 children with high functioning autism (16 males; 4 females)	completed by teachers	correlated with level of functioning - Teachers expressed more concern over long term outcomes for children with higher functioning autism
<b>Tissot (2009)</b>	<i>Sexuality Case Studies</i> 6 cases involving 7 individuals with autism (6 males; 1 female)	Case studies (analysis of meeting notes and student progress notes; staff interviews; observations)	Main themes included: - Misperceptions about children's sexual and non-sexual behaviours - Challenges discussing sexuality with children and professionals. --Sexuality information communicated with children. - Parental worry towards children's future.  - Presence of problematic sexual behaviours addressed through 6-step multi-stakeholder program - Varying degrees of success in reducing problematic behaviours and increasing appropriate behaviours in 5 out of 6 cases
<b>Hénault (2003)</b>	<i>Sexuality Education Interventions</i> 27 adolescent and adult participants with high-functioning autism/Asperger syndrome (23 male; 4 female)	10 week intervention program with four groups using multiple baseline design	- Program effective at increasing participants' sexual knowledge and positive attitudes towards sexuality. - Program effective at increasing social and intimacy skills while decreasing inappropriate behaviours - Gains generally maintained post-intervention


Study	Sample Size and Description	Research Methodology	Major Findings
<b>Roth (2009)</b>	6 adolescent participants (all male) with high-functioning autism and their parents	8 week group intervention program for youth and (separate) parents	<ul style="list-style-type: none"> <li>- Positive overall outcomes, with increased comfort and goal attainment for some families</li> <li>- No significant changes regarding increased youth knowledge or parental worry and acceptance.</li> <li>- Lack of generalization and maintenance over time</li> </ul>

## Appendix C: Visual Representation of Conceptual Framework and Linkages to Research Questions

Research Question 1: Blue  
 Research Question 2: Yellow  
 Research Question 3: Red



## Appendix D: Sample Recruitment Poster (English)



**RESEARCH STUDY:**

**CONCEPTUALIZATIONS OF SEXUALITY EDUCATION FOR YOUTH WITH AN AUTISM SPECTRUM DISORDER**

**Purpose**

- *To understand what sexuality education means for youth with an Autism Spectrum Disorder and their parents*
- *To identify some of the supports and barriers that exist for youth and their parents with regards to sexuality education*

**Who should participate?**

- *Youth with high-functioning autism/Asperger syndrome between the ages of 12 and 18*
- *Parents of youth with high-functioning autism/Asperger syndrome between the ages of 12 and 18*




**What is involved?**

- *Participate in a survey that will take about 30 minutes to complete*
- *Option of also participating in an interview that will take approximately 30 minutes*

***For more information or to participate in this research study, please contact:***

***Nathalie A. Gougeon at e-mail address or phone number***

***This research has received ethics clearance from the University of Ottawa and CHEO Research Ethics Boards***




**CHILDREN'S HOSPITAL  
OF EASTERN ONTARIO**  
401 Appleton Ave., Ottawa, ON K1H 6L1  
tel: 613-737-9121

**CENTRE HOSPITALIER POUR  
ENFANTS DE L'EST DE L'ONTARIO**  
401, rue de l'Église, Ottawa, ON K1H 6L1  
tél: 613-737-9121

**www.cheo.on.ca**

## Appendix E: Sample Recruitment Poster (French)



**ÉTUDE DE RECHERCHE :**

**CONCEPTUALISATIONS DE L'ÉDUCATION À LA SEXUALITÉ POUR LES JEUNES PRÉSENTANT UN TROUBLE DU SPECTRE AUTISTIQUE**

**Objectifs**

- *Comprendre ce que signifie l'éducation à la sexualité pour les jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger et pour leurs parents*
- *Cerner les obstacles que rencontrent les jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger et leurs parents ainsi que les soutiens à leur disposition, dans le domaine de l'éducation à la sexualité*

**Qui est encouragé à participer à cette étude?**

- *Les jeunes de 12 à 18 ans qui présentent l'autisme de haut niveau/le syndrome d'Asperger*
- *Les parents de jeunes de 12 à 18 ans qui présentent l'autisme de haut niveau/le syndrome d'Asperger*




**En quoi consiste la participation à cette étude?**

- *Participation à un sondage d'environ 30 minutes*
- *Option de participer aussi à une entrevue de 30 minutes environ*

*Pour de plus amples renseignements ou pour participer à cette étude de recherche, veuillez contacter :*

*Nathalie A. Gougeon adresse électronique ou numéro de téléphone*

*Cette étude a reçu l'approbation des comités d'éthique de l'Université d'Ottawa et du CHEO.*



**CHILDREN'S HOSPITAL OF EASTERN ONTARIO**  
37, Street Park, Ottawa, ON K1R 5B1  
TEL: 613-237-7522

**CENTRE HOSPITALIER POUR ENFANTS DE L'EST DE L'ONTARIO**  
400, rue de la Paix, Ottawa, QC K1R 5B1  
TEL: 613-237-7522

**www.cheo.on.ca**

## Appendix F: Introductory Letter (English)



Month Date, Year

Hello,

You are invited to participate in a study looking at the sexuality education needs and experiences of youth with high-functioning autism/Asperger syndrome and their families. This study is being conducted by Nathalie A. Gougeon as part of a requirement for a Doctorate of Philosophy in Education from the University of Ottawa. The purpose of this study is to better understand what sexuality education means for youth with an Autism Spectrum Disorders and their parents and to identify some of the supports and barriers that exist for youth and their parents with regards to sexuality education. This study is aimed at youth with high-functioning autism/Asperger syndrome between the ages of 12 and 18, and their parents.

Participation in this study will involve completing a survey, which should take about 30 minutes. The survey will ask your opinion about various aspects of sexuality education for your child, your child's sexual behaviours (for example, seeking privacy, touching self and others), positive and negative experiences (for example, dating, sexual bullying), and so forth. There is also the option of participating in an interview that should take about 30 minutes to complete. The interview will ask your opinion related to sexuality education, what topics should be covered as part of sexuality education, who should be responsible for providing it, and so forth. Some of the questions being asked within this study are personal in nature.

This study will give you the opportunity to express your opinion and to provide the main researcher with valuable information on how to improve the delivery of sexuality education to youth with autism and their families. We hope that your information will help to develop curriculum in the future, as well as provide information that will eventually improve policies and programs for youth with autism. However, there are no benefits from participating in this study; if your family is currently on the waitlist for ABA services, participating in this study will **not** change your position on this waitlist.

Your participation is voluntary and there is no consequence if you do not participate. The results of this study will be published in the main researcher's doctoral thesis. In addition, the results of this study will be summarized in a report which will be shared with the individuals who have an interest in the results, including parents and youth participating in this study, as well as partner agencies. There is also the possibility that research results will be presented at conferences or published in peer-reviewed journals. While the information may also be used in future publications and presentations, it will remain confidential and all survey information will be reported as combined information.

If you are interested in learning more about and/or participating in this study, please complete the attached *Consent to Contact* form and return it in the envelope included with this letter.

Should you have any questions or require more information about the study, please contact:

Main Researcher, PhD Candidate, MS Ed, BCBA:  
Nathalie Gougeon, phone number & e-mail address

This project has received ethics clearance from the University of Ottawa and CHEO Research Ethics Boards

Sincerely,

Name  
Director – CHEO Autism Program of Eastern Ontario

## Appendix G: Introductory Letter (French)



Jour/mois/année

Bonjour,

Nous vous invitons à participer à une étude concernant les besoins et l'expérience des jeunes qui présentent l'autisme de haut niveau/le syndrome d'Asperger et de leurs familles dans le domaine de l'éducation à la sexualité. Cette étude sera menée par Nathalie A. Gougeon, dans le cadre d'un doctorat en Éducation à l'Université d'Ottawa. L'objectif de cette étude est de parvenir à une meilleure compréhension de ce que signifie l'éducation à la sexualité pour les jeunes atteints d'autisme et leurs parents, et de cerner les soutiens et les obstacles qui existent pour ces jeunes et leurs familles dans le domaine de l'éducation à la sexualité. Cette étude s'adresse aux jeunes de 12 à 18 ans qui présentent l'autisme de haut niveau/le syndrome d'Asperger ainsi qu'à leurs parents.

La participation à cette étude consistera à répondre à un sondage, qui devrait prendre environ 30 minutes. Dans ce sondage, on vous demandera votre opinion concernant divers aspects de l'éducation à la sexualité de votre enfant, les comportements sexuels de votre enfant (comme sa recherche de l'intimité, le fait que votre enfant se touche ou touche les autres, etc.), ses expériences positives et négatives (ses relations sentimentales, l'intimidation sexuelle, etc.). Vous pourrez également participer à une entrevue d'environ 30 minutes, si vous le désirez. Si vous choisissez de participer à une entrevue, vous aurez la possibilité d'y exprimer plus amplement votre opinion concernant l'éducation à la sexualité, en particulier concernant quels sujets devraient être abordés dans l'éducation sexuelle, qui devrait avoir la responsabilité de l'enseigner, etc. Certaines des questions qui seront posées dans le cadre de cette étude sont de nature personnelle.

Cette étude vous permettra ainsi d'exprimer votre point de vue et de fournir à la chercheuse des informations importantes concernant l'enseignement de l'éducation sexuelle auprès des jeunes atteints d'autisme et de leurs familles. Notre espoir est que les renseignements que vous nous fournirez nous permettront d'élaborer un curriculum adapté ainsi que d'améliorer les politiques et les programmes dans le domaine de l'éducation sexuelle pour ces jeunes. Veuillez noter, toutefois, que la participation à l'étude ne présente aucun avantage immédiat pour les participants : si votre famille est actuellement sur la liste d'attente pour des services d'ACA, votre participation à cette étude ne changera rien à votre rang sur cette liste.

La participation à cette étude est volontaire; vous pouvez choisir de ne pas y participer sans aucune conséquence. Les constatations de l'étude seront publiées dans la thèse de doctorat de la chercheuse. De plus, les résultats de cette étude seront résumés dans un rapport qui sera communiqué aux personnes intéressées, y compris aux jeunes atteints d'autisme et aux parents qui auront participé à l'étude ainsi qu'aux agences de santé partenaires du CHEO. Il est possible également que les résultats de cette étude seront présentés à des conférences ou dans des revues scientifiques à comité de lecture; dans ce cas, toutes les données demeureront strictement confidentielles et elles seront présentées dans leur ensemble.

Si vous désirez en apprendre davantage au sujet de cette étude ou participer à l'étude, veuillez remplir le formulaire de consentement à être contacté ci-joint et nous le retourner dans l'enveloppe incluse.

Pour toute autre question concernant cette étude, n'hésitez pas à contacter la chercheuse :  
Nathalie Gougeon, candidate au doctorat, MS Ed, BCBA  
Numéro de téléphone, adresse électronique

Cette étude a reçu l'approbation des comités de déontologie de l'Université d'Ottawa et du CHEO.

Cordialement,  
Directrice – programme d'autisme de l'Est de l'Ontario – CHEO

## Appendix H: Consent to Contact Form (English)



### Conceptualizations of Sexuality Education for Youth with an Autism Spectrum Disorder

We are currently looking at how different people define sexuality education for youth with high-functioning autism/Asperger syndrome. Information from this study will help us understand the needs in this area. This will help to provide information and develop future programs, theory, and policies.

We are looking to conduct surveys and/or interview with youth between the ages of 12 and 18 who have high-functioning autism/Asperger syndrome, as well as their parents/caregivers.

**Please indicate below if you are willing to be contacted to hear more about the study:**

**YES, I am interested in hearing more about this study.**

I (please print name) \_\_\_\_\_ consent to being contacted by the researcher to tell me more about the above-mentioned study. *I understand that by consenting to be contacted, I am under no obligation to participate in this study.*

I am a:  Parent/Caregiver  Youth

My contact information is:

Telephone: \_\_\_\_\_

Email (optional): \_\_\_\_\_

\_\_\_\_\_  
Participant Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Caregiver Signature (if Youth participant under 16)

\_\_\_\_\_  
Date

**NO, I (please print name) \_\_\_\_\_ am not interested in hearing more about this study.**

**Should you have any questions or require more information about the study, please contact the main researcher, Nathalie A. Gougeon (e-mail address)**

## Appendix I: Consent to Contact Form (French)



uOttawa

### Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

Nous examinons actuellement les différentes conceptions de l'éducation sexuelle pour les jeunes atteints d'autisme de haut niveau/du syndrome d'Asperger. Les constatations de cette étude nous permettront de comprendre quels sont les besoins à cet égard, ce qui éclairera l'élaboration de théories, de politiques et de programmes dans ce domaine.

Nous aimerions mener des sondages et/ou des entrevues auprès de jeunes de 12 à 18 ans présentant l'autisme de haut niveau/le syndrome d'Asperger ainsi qu'auprès de leurs parents/responsables.

#### Acceptez-vous d'être contacté(e) pour en apprendre davantage au sujet de cette étude?

**OUI**, j'aimerais avoir de plus amples renseignements concernant cette étude.

Je soussigné(e) \_\_\_\_\_ (votre nom en lettres moulées) accepte que le chercheur me contacte pour me parler de l'étude. *Je comprends que, même si je consens à être contacté(e), cela ne m'oblige aucunement à participer à cette étude.*

Je suis :  un parent/responsable     un jeune

Coordonnées :

Téléphone : \_\_\_\_\_

Adresse courriel (facultatif) : \_\_\_\_\_

\_\_\_\_\_  
Signature du participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature du parent/responsable (si le jeune participant a moins de 16 ans)

\_\_\_\_\_  
Date

**NON**, je soussigné(e) \_\_\_\_\_ (votre nom en lettres moulées) ne désire pas entendre parler de cette étude.

Pour toute question ou renseignement supplémentaire concernant cette étude, n'hésitez pas à contacter la chercheuse : Nathalie A. Gougeon (adresse électronique).

## Appendix J: Coding Scheme for Research Questions and Table of Specifications

Q1: What does *sexuality education* mean for youth with high-functioning autism and their caregivers?

Q1A: What form should sexuality education take according to youth and caregivers?

Q1A-R: Who should be responsible for teaching it?

Q1A-P: How should it be presented?

Q1B: What should be the goals of sexuality education according to youth and caregivers?

Q1B-C: What content should and should not be part of the curriculum?

Q2: How do prior literature, policy, and curricula in this field inform this definition?

Q2A: In what ways is the form of sexuality education similar or different in the literature, policy, and curricula when compared to the form described by youth and caregivers?

Q2B: In what ways are the goals of sexuality education different in the literature, policy, and curricula when compared to the goals identified by youth and caregivers?

Q3: In the context of sexuality education for youth with high-functioning autism, what are the supports and barriers they encounter and what are their impact(s)?

Q3A-IS: What are the individual strengths impacting sexuality education?

Q3A-SS: What are the social/societal supports impacting sexuality education?

Q3B-IB: What are the individual barriers impacting sexuality education?

Q3B-SB: What are the social/societal barriers impacting sexuality education?

Table J1  
*Research Question Table of Specifications*

<b>Research question</b>	<b>Adapted Parenting and Sexuality Scale<sup>a</sup></b>	<b>Adapted Youth Sexuality Development Scales (parent &amp; youth)<sup>b</sup></b>	<b>Interview rubrics (parent &amp; youth)<sup>c</sup></b>	<b>Extant text analysis</b>
Q1: Definition (youth/caregivers)		X	X	
Q1A: Form		X	X	
Q1A-R: Responsibility		X	X	
Q1A-P: Provision		X	X	
Q1B: Purpose		X	X	
Q1B-C: Content		X	X	
Q2: Definition (literature)			X	X
Q2A: Form			X	X
Q2B: Purpose			X	X
Q3: Supports and barriers (youth/caregivers)	X	X	X	
Q3A-IS		X	X	
Q3A-SS	X	X	X	
Q3B-IB		X	X	
Q3B-SB	X	X	X	

<sup>a</sup>See Appendix K for coded *Adapted parenting and sexuality scale*.

<sup>b</sup>See Appendix K for coded *Adapted youth sexuality scale*.

<sup>c</sup>See Appendix O for coded interview rubric.

## Appendix K: Caregiver Consent Form and Survey (English)



uOttawa

### **PARENT SURVEY CONSENT FORM**

**Title of Study:** Conceptualizations of Sexuality Education for Youth with an Autism Spectrum Disorder

**Main Researcher :** Nathalie A. Gougeon, PhD Candidate, MS Ed, BCBA

#### **INTRODUCTION**

This study is being conducted as part of a Doctorate of Philosophy in Education from the University of Ottawa. Please take a moment to read and carefully consider the information below before you give your consent to take part in this study. This information will describe the purpose and procedures, as well as the possible risks and benefits of the study. You are encouraged to ask any questions you may have about the study to the main researcher of this study. A copy of this consent form has been included for you to keep. This study will be conducted in both English and French and you will have the choice of which language you would prefer.

#### **PURPOSE:**

You are invited to participate in a study looking at the sexuality education needs and experiences of youth with high-functioning autism/Asperger syndrome and their families. Some of the questions being asked within this study are personal in nature. The survey will ask your opinion about various aspects of sexuality education for your child, your child's sexual behaviours (for example, seeking privacy, touching self and others), positive and negative experiences (for example, dating, sexual bullying), and so forth.

#### **PROCEDURES**

You are being asked to take part in a survey about your experience as a parent of a child with high-functioning autism/Asperger syndrome.

The survey will take approximately 30 minutes to complete. No one other than the main researcher and/or thesis committee members will have access to this survey. You will have the option to complete the survey in either English or French.

#### **POSSIBLE BENEFITS**

There are no benefits from participating in this study; if your family is currently on the waitlist for ABA services, participating in this study will **not** change your position on this waitlist. However, this study will give you the opportunity to express your opinion and to provide the main researcher with valuable information on how to improve the delivery of sexuality education to youth with autism and their families. We hope that your information will help to develop curriculum in the future, as well as provide information that will eventually improve policies and programs for youth with autism.

#### **POSSIBLE RISKS**

Because of the sensitive nature of the subject matter, you may feel uncomfortable answering some of the questions. The researcher will try to reduce any potential risks by making sure that all information is kept confidential, whenever possible. If you feel uncomfortable answering any of the questions in this survey, you may choose not to answer them, and if you wish to stop the survey, you are free to do so at any time. If you choose to share personal information that involves illegal or dangerous behaviours (for example, if your child was a victim of sexual abuse or bullying), the researcher will be required by law to share this information with proper authorities (for example, the Children's Aid Society or police services). If you share information that may require additional resources, the researcher will contact you to provide you with information on available resources and/or community agencies that can support this situation.

### **CONFIDENTIALITY**

Unless required by law, all information collected during the study will be kept entirely confidential and will be stored in a secure location at the offices of the Autism Program of Eastern Ontario. The study information will be stored at the Autism Program of Eastern Ontario for 7 years following the completion of the study, after which time all raw information, transcripts/field notes will be shredded and audio recordings will be erased. All transcripts, field notes and audio files will be password protected and stored on an encrypted USB stick. All computers on which information will be stored will be password protected. Only the above-mentioned researchers will have access to the information. In order to keep your answers anonymous, a unique code will be assigned to all information collected about you. Your code will not be based on any identifying information (date of birth, for example).

### **PARTICIPATION**

Your participation in the study is entirely voluntary. You are under no obligation to participate. You can decline to answer any questions and *you have the right to withdraw from the study at any time, without consequence.*

### **RESULTS**

The results of this study will be published in the main researcher's doctoral thesis. In addition, the results of this study will be summarized in a report which will be shared with the individuals who have an interest in the results, including parents and youth participating in this study, as well as partner agencies. There is also the possibility that research results will be presented at conferences or published in peer-reviewed journals. While the information may also be used in future publications and presentations, it will remain confidential and all survey information will be reported as combined information.

### **CONTACT INFORMATION**

Should you have any questions or require more information about the study, please contact:

**Main Researcher, PhD Candidate, MS Ed, BCBA :**

*Nathalie Gougeon, phone number, e-mail address*

The CHEO Research Ethics Board (REB) has approved this study. The REB is a group of individuals from scientific and non-scientific backgrounds who review research study projects. Their goal is to ensure the protection of the rights and welfare of people involved in research. For information regarding patients' rights in research studies, you may contact the Chair of the Research Ethics Board at *phone number*, although this person cannot provide any health-related information about the study.



**PARENT SURVEY CONSENT FORM**

**Title of Study:** Conceptualizations of Sexuality Education for Youth an Autism Spectrum Disorder

**Principal Investigators:** Nathalie A. Gougeon, PhD Candidate, MS Ed., BCBA

- I have read and /or been informed of and I understand the above information. I have had the opportunity to ask questions and my questions have been addressed to my satisfaction.*
- I have retained a copy of this signed consent form.*
- I would like to receive a summary of the results at the end of the study.*

I \_\_\_\_\_ agree to participate in a survey for this study. *(please print your name)*

Telephone Number: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

\_\_\_\_\_

E-mail Address (optional): \_\_\_\_\_

\_\_\_\_\_  
Participant's name

\_\_\_\_\_  
Participant's signature

Date signed

\_\_\_\_\_  
Investigator's name

\_\_\_\_\_  
Investigator's signature

Date signed

Research ID: \_\_\_\_\_

Are you the parent of a child with high-functioning autism/Asperger Syndrome?

Yes                      No

Is your child between the ages of 12 and 18?

Yes                      No

Note: If you have answered NO to any of the above questions, you are not eligible to participate in the study. Thank you for your time.

### **Adapted Parenting and Sexuality Scale<sup>14</sup>**

Listed below are a number of statements. Please respond to each item indicating your agreement or disagreement with each statement in the following manner:

- 1= Not true at all
  - 2= Mostly not true
  - 3= Somewhat true
  - 4 = Mostly true
  - 5= Very true
- 

(Q3A-SS/Q3A-SB) 1. I am accepting of my child as a sexual person.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 2. I have all of the skills I need to address sexuality issues with my child as they arise.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 3. I worry about my child's sexual development.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 4. I use effective teaching methods appropriate for my child's learning style when teaching my child about sexuality.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 5. I do not feel competent as a sexual educator for my child.

1      2      3      4      5

---

<sup>14</sup> Adapted from Nichols, S. (2005). *Parenting and sexuality scale*®. Used with permission.

(Q3A-SS/Q3A-SB) 6. I have the knowledge I need about anatomy, physiology, biology, etc. if my child were to ask me a question about one of these topics.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 7. I am comfortable talking with my child about sexuality.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 8. I have developed a plan for my child's sexual learning.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 9. I am able to research information to help me better understand my child's sexual development.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 10. I feel confident in my ability to help my child grow and develop in their sexuality.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 11. I have a good understanding of typical sexual development during puberty and adolescence.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 12. Thinking about my child as a sexual person makes me tense and anxious.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 13. I am accepting of my child exploring his/her sexuality in a socially appropriate manner.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 14. I feel that it is acceptable and natural for my child to masturbate.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 15. I am experienced in teaching my child about sexuality.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 16. I do not feel able to advocate for my child around issues related to his/her sexuality.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 17. I have good judgment about protecting my child but also enabling sexual learning experiences.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 18. I am too worried about my child to be hopeful about their sexual learning and development.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 19. I am able to handle problems that arise with my child's sexual behaviour and development.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 20. I know what resources are available to help me with teaching my child about sexuality, puberty, and growing up.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 21. I am anxious about my child's sexual behaviour when he/she is not supervised.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 22. I would feel comfortable talking about my child's sexuality/sexual behaviour with his/her teacher or educator if concerns arose.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 23. I am able to communicate effectively with my child about sexuality and puberty.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 24. I worry that my child will be abused.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 25. When I think about sexuality and my child, I focus on all the bad things that can happen.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 26. I have talked with my child's doctor about my child's sexual development.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 27. I am aware of the sexuality issues related to my child's disorder.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 28. I am able to make good decisions about what my child needs with respect to his/her sexual learning.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 29. I have learned what I need to know to help foster my child's sexual development and learning.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 30. I would like my child to ask me questions about sexuality and growing up.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 31. I want my child to have a sexual relationship when they are ready and if they choose to.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 32. Addressing issues related to my child's sexual development with his/her doctor makes me feel uncomfortable.

1      2      3      4      5

(Q3A-SS/Q3A-SB) 33. I feel very inexperienced with regards to addressing my child's sexual development.

1      2      3      4      5

## Adapted Youth Sexuality Development Scale<sup>15</sup>

Please answer the following questions regarding your child's sexuality development, behaviour, experiences, and learning.

### Privacy

(Q1B-C/Q3A-IS/Q3B-IB)1. Does your child know which body parts are private?

\_\_\_\_\_ Not at all  
\_\_\_\_\_ Somewhat  
\_\_\_\_\_ Yes

(Q1B-C/Q3A-IS/Q3B-IB)2. Does your child respect other people's privacy?

\_\_\_\_\_ Not at all  
\_\_\_\_\_ Somewhat  
\_\_\_\_\_ Yes

(Q1B-C/Q3A-IS/Q3B-IB)3. Does your child seek privacy (circle your answer):

While dressing/undressing

Never Rarely Sometimes Often Always Don't Know Not Applicable

When bathing or showering

Never Rarely Sometimes Often Always Don't Know Not Applicable

While using the toilet

Never Rarely Sometimes Often Always Don't Know Not Applicable

While masturbating

Never Rarely Sometimes Often Always Don't Know Not Applicable

When he/she wants to be alone

Never Rarely Sometimes Often Always Don't Know Not Applicable

---

<sup>15</sup> Adapted from Nichols, S. (2005). *Youth sexuality development scale*<sup>©</sup>. Used with permission.

(Q1B-C/Q3A-IS/Q3B-IB) **4. Does your child understand the following rules about privacy (circle your answer):**

Touch own private body parts in private places only

Not at all      Somewhat      Yes

Close the bathroom door

Not at all      Somewhat      Yes

Undress in private

Not at all      Somewhat      Yes

Undo pants only in bathroom or bedroom

Not at all      Somewhat      Yes

Don't walk around the house nude

Not at all      Somewhat      Yes

Knock on closed doors and wait to be asked to enter

Not at all      Somewhat      Yes

(Q1A-P) **5. How did you teach your child about rules concerning privacy? (check all that apply)**

- Modeling appropriate behaviours
- Providing instructions and directions
- Repeating instructions
- Providing parental discipline
- Rewarding and reinforcing appropriate behaviour
- Others:

---

Comments about privacy:
-------------------------

## **Behaviours**

(Q1B-C/Q3A-IS/Q3B-IB)1. **Has your child ever touched his/her private body parts in public?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3A-IS/Q3B-IB)2. **Has your child ever masturbated in a public place?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3A-IS/Q3B-IB)3. **Has your child ever masturbated with unusual or dangerous objects (for example, socks, food)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3A-IS/Q3B-IB)4. **Has your child ever refused to touch his or her private body parts (for example, penis, vagina)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3A-IS/Q3B-IB)5. **Has your child ever intruded on another person's personal space (for example, stands too close)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3A-IS/Q3B-IB)6. **Has your child ever touched another person in an inappropriate way (for example, attempted to hug or kiss, attempted to touch private body parts)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3A-IS/Q3B-IB)7. **Has your child ever removed his or her clothing in public when it was inappropriate to do so?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

**If you answered yes, when was the last time your child removed his/her clothing in public? How old were they?**

---

(Q1B-C) 8. **Has your child looked at Internet porn sites?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3A-IS/Q3B-IB)9. **Does your child talk about sexuality and sexual activities in a way that is not appropriate for youth his/her age?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3A-IS/Q3B-IB)**10. Has your child ever acted in an inappropriate way towards someone whom they were romantically interested (for example, called them too frequently, followed them around school)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

Specify behaviour:

---

(Q1B-C/Q3A-IS/Q3B-IB)**11. Has your child developed sexual obsessions (for example, sexuality has become the sole source of interest and stimulation such as: obsessed with idea of having sex, obsessed with having a girlfriend, compulsive masturbation, repetitive fantasies)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

Specify obsession:

---

(Q1B-C/Q3B-IB)**12. Other challenging behaviours not mentioned here?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

Specify behaviour:

---

Comments about behaviours:



**Experience**

**(Q1B-C) 1. Has your child expressed a romantic interest in anyone (for example, said a girl is cute)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

**(Q1B-C) 2. Has your child gone on a date (for example, to a movie, to prom)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

**(Q1B-C) 3. Has your child had a boyfriend or girlfriend (for example, someone they have dated more than 5 times)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

**(Q1B-C) 4. Has your child expressed confusion or conflict about their gender identity (for example, belonging to the female or male sex)?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

**(Q1B-C) 5. Has your child expressed a romantic interest in individuals of the same sex?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

**(Q1A-R/Q1B-C) 6. As part of healthy development, has your child had a complete physical examination by a doctor of their sexual body parts?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

**If you answered YES, or PLANNING TO, how did you/will you prepare your child for this appointment?**

---

---

Comments about experience:
----------------------------

## **Growing Up**

(Q1B-C/Q3B-IB) **1. Has your child ever expressed fear, worry, anxiety, or nervousness about growing up?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3B-IB) **2. Has your child expressed a strong desire to NOT grow up?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

(Q1B-C/Q3B-IB) **3. Has your child expressed fear/worry/concern changes related to puberty?**

Never Rarely Sometimes Often Always Don't Know Not Applicable

## **Bullying**

(Q1B-C/Q3B-SB) **1. Has your child ever experienced sexual bullying such as (please check):**

- being "flashed" or "mooned" (someone exposing their privates to your child)
- having sexual rumours spread about him/her
- being teased about sexual orientation
- being taunted or teased about sexual body parts (for example being told "hey, nice boobs")
- lewd and sexual gestures or looks (for example, making a masturbating gesture)
- being subject to sexual comments or jokes
- receiving phone calls or texts of a sexual nature
- being passed unwanted notes, messages, photographs, or pictures about sex
- being called a derogatory term associated to their sexual orientation (for example, being called "fag", "homo", "dyke", "queer", "gay", "lesbo")
- having their clothes pulled in a sexual way
- being teased about their attractiveness (for example, "you're fat and ugly")
- being brushed up against in a sexual way
- being touched, grabbed, or pinched in a physically intrusive sexual way
- being forced to kiss a peer
- being forced by a peer to do something sexual other than kissing
- being spied on while dressing or showering at school
- having sexual messages/graffiti written about them on bathroom walls, the locker room, on the Internet via social media pages, etc.
- Other: \_\_\_\_\_
- Other: \_\_\_\_\_

**2. If you answered YES to any of the above, how frequently does the sexual bullying occur:**

- once a month or less
- a few times a month
- once a week
- a few times a week

\_\_\_\_\_ almost every day

(Q3A-SS/Q3B-SB) 3. If you answered YES to the above questions about sexual bullying, have you tried to address these issues with your child's school?

\_\_\_\_\_ no

\_\_\_\_\_ yes

\_\_\_\_\_ not yet, but planning to

Comments about growing up and bullying:

### **Demographic Information**

Your age: \_\_\_\_\_

Child's age: \_\_\_\_\_

Your gender: \_\_\_\_\_

Child's gender: \_\_\_\_\_

Any other comments about this survey:

***Please return this completed survey, along with the signed consent form in the self-addressed stamped envelope included in this package.***

***If you are also interested in participating in the interview portion of this study, please also complete and return the Consent to Contact form.***

***Thank you for your time.***

## Appendix L: Caregiver Consent Form and Survey (French)



### FORMULAIRE DE CONSENTEMENT À UN SONDAGE À L'INTENTION DES PARENTS

**Titre de l'étude :** Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

**Chercheure :** Nathalie A. Gougeon, candidate au doctorat, MS Ed, BCBA

#### INTRODUCTION

La chercheure mène cette étude dans le cadre de son doctorat en Éducation (Université d'Ottawa). Nous vous remercions d'avance de prendre le temps de lire les renseignements qui suivent très attentivement avant de consentir à participer à l'étude. Les renseignements ci-dessous expliquent l'objectif de l'étude, son déroulement, ainsi que ses risques et avantages potentiels. Nous vous encourageons à obtenir tout renseignement supplémentaire auprès de la chercheure. Nous vous remettons une copie de ce formulaire, que vous pourrez conserver. L'étude sera menée en français et en anglais : vous aurez donc le choix d'y participer dans l'une ou l'autre de ces langues.

#### OBJECTIF DE L'ÉTUDE

Vous êtes invité(e) à participer à une étude qui examinera les besoins et l'expérience des jeunes atteints d'autisme de haut niveau/du syndrome d'Asperger et de leurs familles dans le domaine de l'éducation à la sexualité. Certaines des questions qui seront posées dans le cadre de cette étude sont de nature personnelle. Dans le sondage, on vous demandera de donner votre opinion concernant divers aspects de l'éducation à la sexualité de votre enfant et de parler de ses comportements sexuels (de sa recherche de l'intimité, de son habitude de se toucher ou de toucher d'autres personnes, par exemple), de ses expériences positives et négatives (relations intimes ou bullying/harcèlement sexuel, par exemple), etc.

#### DÉROULEMENT DE L'ÉTUDE

Nous vous invitons à participer à un sondage où vous pourrez parler de votre expérience à titre de parent/responsable d'un jeune qui présente l'autisme de haut niveau/le syndrome d'Asperger.

Le sondage durera environ 30 minutes. Personne n'aura accès à vos réponses au sondage en dehors de la chercheure et des membres de son comité de thèse. Vous aurez le choix de faire le sondage en français ou en anglais.

#### AVANTAGES POTENTIELS

La participation à cette étude ne présente aucun avantage pour les participants; si votre famille est actuellement sur une liste d'attente pour recevoir des services d'ACA, votre participation à cette étude ne changera **pas** votre position sur cette liste. Toutefois, cette étude vous donnera la possibilité d'exprimer votre point de vue et de fournir à la chercheure des informations importantes concernant les moyens d'améliorer la prestation de l'éducation à la sexualité auprès des jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger et de leurs familles. Notre espoir est que les informations que vous nous fournirez nous permettront d'élaborer un curriculum pertinent et, par la suite, d'améliorer les politiques et les programmes pour les jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger.

#### RISQUES POTENTIELS

Étant donné la nature délicate du sujet, il est possible que vous vous sentiez mal à l'aise de répondre à certaines des questions. La chercheure s'efforcera de réduire ce risque potentiel en s'assurant, dans la mesure du possible, que vos

informations demeureront confidentielles. La chercheuse fera également tout son possible pour que vous vous sentiez à l'aise tout au long du sondage. Si, toutefois, vous vous sentiez mal à l'aise à n'importe quel moment au cours du sondage, vous serez entièrement libre de sauter une question; vous êtes également entièrement libre de vous retirer de ce sondage à n'importe quel moment. Si vous décidez de partager avec la chercheuse des informations personnelles qui concernent des comportements dangereux ou illégaux (au cas, par exemple, où votre enfant a été victime d'abus sexuels ou de bullying/harcèlement sexuel), la chercheuse sera dans l'obligation légale de faire part de ces informations aux autorités pertinentes (Société d'aide à l'enfance ou services de police, par exemple). Si vous partagez avec la chercheuse des informations qui pourraient exiger des ressources supplémentaires, la chercheuse vous fournira des renseignements sur les ressources disponibles ou les agences communautaires qui pourraient vous apporter un soutien dans ces situations.

### **CONFIDENTIALITÉ**

À moins que la loi ne l'exige, toutes les informations qui seront recueillies au cours de cette étude demeureront strictement confidentielles et elles seront conservées en lieu sûr aux bureaux du Programme d'autisme de l'Est de l'Ontario. Les informations recueillies dans cette étude seront conservées aux bureaux du Programme d'autisme de l'Est de l'Ontario pendant une période de 7 ans suivant la fin de l'étude; après cette période, toutes les informations brutes, transcriptions et notes de terrain seront déchiquetées et tous les enregistrements seront effacés. Toutes les transcriptions et notes de terrain et tous les fichiers audio seront protégés par un mot de passe et conservés sur une clé USB chiffrée. Tous les ordinateurs sur lesquels des informations seront conservées seront protégés par un mot de passe. Seule la chercheuse citée précédemment aura accès à ces informations. Pour que vos réponses demeurent anonymes, un code unique sera donné à toutes les informations qui auront été recueillies à votre sujet. Votre code n'aura aucun rapport avec les renseignements qui permettraient de connaître votre identité (tels que date de naissance ou autre).

### **PARTICIPATION**

Votre participation à cette étude est absolument volontaire. Vous n'êtes aucunement obligé(e) de participer. Vous avez également le droit de refuser de répondre à n'importe quelle question et *vous avez le droit de vous retirer de l'étude à n'importe quel moment sans aucune conséquence.*

### **RÉSULTATS**

Les résultats de cette étude seront publiés dans la thèse de doctorat de la chercheuse. De plus, ces résultats seront résumés dans un rapport qui sera remis aux personnes qui s'intéressent aux constatations de l'étude, y compris aux parents et aux jeunes qui auront participé à cette étude et aux agences qui travaillent en partenariat avec le Programme d'autisme de l'Est de l'Ontario. Il est possible également que les résultats de cette étude soient présentés à des conférences ou publiés dans des revues scientifiques à comité de lecture. Si les informations recueillies dans cette étude sont utilisées dans des publications ou pour des présentations professionnelles, elles demeureront totalement confidentielles et seront présentées dans leur ensemble.

### **POUR TOUT RENSEIGNEMENT SUPPLÉMENTAIRE**

Si vous désirez de plus amples renseignements concernant cette étude, n'hésitez pas à contacter la chercheuse :

**Nathalie Gougeon - candidate au doctorat, MS Ed, BCBA :**

*Tél. : numéro de téléphone, adresse électronique*

Cette étude a reçu l'approbation du Comité d'éthique de la recherche du CHEO. Le Comité regroupe des scientifiques et des non-scientifiques dont la mission est d'évaluer les projets de recherche qui leur sont soumis. Ils ont la responsabilité d'assurer la protection des droits et du bien-être des personnes qui participent à des études de recherche. Pour tout renseignement concernant les droits des participants à une étude de recherche, vous pouvez contacter le président du Comité d'éthique de la recherche du CHEO, au numéro de téléphone. Veuillez noter, toutefois, que cette personne ne peut fournir aucun renseignement de santé concernant cette étude.



uOttawa

## FORMULAIRE DE CONSENTEMENT À UN SONDAGE POUR LES PARENTS

**Titre de l'étude :** Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

**Chercheure :** Nathalie A. Gougeon, candidate au doctorat, MS Ed., BCBA

- J'ai lu les renseignements qui précèdent ou on m'en a informé(e), et je comprends ces renseignements. On m'a donné la possibilité de poser des questions et on a répondu à mes questions de façon satisfaisante.*
- On m'a remis une copie de ce formulaire de consentement dûment rempli et signé.*
- J'aimerais recevoir un résumé des résultats à la fin de l'étude.*

Je soussigné(e) \_\_\_\_\_ (votre nom en lettres moulées) accepte de participer à un sondage dans le cadre de cette étude.

N° de téléphone : \_\_\_\_\_

Adresse postale : \_\_\_\_\_

\_\_\_\_\_

Adresse courriel (facultatif) : \_\_\_\_\_

\_\_\_\_\_  
Nom du participant

\_\_\_\_\_  
Signature du participant

\_\_\_\_\_  
Date de signature

\_\_\_\_\_  
Nom de la chercheure

\_\_\_\_\_  
Signature de la chercheure

\_\_\_\_\_  
Date de signature

Code de recherche : \_\_\_\_\_

Êtes-vous le parent d'un enfant avec l'autisme de haut niveau/le syndrome d'Asperger?

Oui                      Non

Est-ce que votre enfant a entre 12 et 18 ans?

Oui                      Non

Note : Si vous avez répondu NON à l'une des questions qui précèdent, vous ne pouvez pas participer à cette étude. Nous vous remercions toutefois que votre intérêt pour cette recherche.

### **Échelle adaptée de l'exercice des responsabilités parentales et de la sexualité<sup>16</sup>**

Ci-dessous, vous trouverez un certain nombre de déclarations. Pour chacune de ces déclarations, veuillez indiquer dans quelle mesure vous êtes d'accord (ou pas d'accord) de la façon suivante :

- 1= Faux
- 2= Essentiellement faux
- 3= Un peu vrai
- 4= Essentiellement vrai
- 5= Très vrai

---

1. J'accepte le fait que mon enfant est une personne sexuelle.

1      2      3      4      5

2. Je possède toutes les habiletés nécessaires pour gérer avec mon enfant les questions de sexualité qui se présentent.

1      2      3      4      5

3. J'ai des inquiétudes concernant le développement sexuel de mon enfant.

1      2      3      4      5

4. Quand je parle de sexualité avec mon enfant, j'utilise des méthodes d'enseignement efficaces qui conviennent à son style d'apprentissage.

1      2      3      4      5

---

<sup>16</sup> Adapted from Nichols, S. (2005). *Parenting and sexuality scale*®. Used with permission.

5. Je ne me sens pas compétent(e) pour faire l'éducation sexuelle de mon enfant.

1      2      3      4      5

6. Si mon enfant me posait une question concernant anatomie, physiologie, biologie ou autre, je possède les connaissances nécessaires pour lui répondre.

1      2      3      4      5

7. Je me sens à l'aise quand je parle de sexualité avec mon enfant.

1      2      3      4      5

8. J'ai dressé un plan pour l'éducation sexuelle de mon enfant.

1      2      3      4      5

9. Je sais rechercher des informations pour mieux comprendre le développement sexuel de mon enfant.

1      2      3      4      5

10. Je suis certain(e) que je suis capable d'aider mon enfant à s'épanouir dans sa sexualité.

1      2      3      4      5

11. J'ai une bonne compréhension du développement sexuel typique au moment de la puberté et dans l'adolescence.

1      2      3      4      5

12. Je ressens tension et anxiété quand je pense à mon enfant en tant que personne sexuelle.

1      2      3      4      5

13. J'accepte le fait que mon enfant a le droit d'explorer sa sexualité d'une manière socialement acceptable.

1      2      3      4      5

14. Je considère qu'il est acceptable et naturel que mon enfant se masturbe.

1      2      3      4      5

15. J'ai l'habitude de parler de sexualité à mon enfant.

1      2      3      4      5

16. Quand il s'agit de questions reliées à sa sexualité, je ne me sens pas capable de défendre les intérêts de mon enfant.

1      2      3      4      5

17. J'ai un bon jugement pour ce qui est de protéger mon enfant, et aussi, pour ce qui est de lui laisser la liberté de connaître des expériences sexuelles.

1      2      3      4      5

18. J'ai de trop grandes inquiétudes au sujet de mon enfant pour avoir un espoir concernant son éducation sexuelle ou son développement sexuel.

1      2      3      4      5

19. Je réussis à gérer les problèmes associés au comportement sexuel et au développement sexuel de mon enfant.

1      2      3      4      5

20. Je suis au courant des ressources qui sont disponibles pour m'aider à parler à mon enfant de sexualité, de la puberté et du développement.

1      2      3      4      5

21. Quand je sais que mon enfant est sans supervision, je m'inquiète de son comportement sexuel.

1      2      3      4      5

22. En cas d'inquiétudes, je me sentirais à l'aise de parler de la sexualité/du comportement sexuel de mon enfant avec son enseignant ou avec un autre éducateur.

1      2      3      4      5

23. Je suis capable de parler de sexualité et de la puberté avec mon enfant de manière efficace.

1      2      3      4      5

24. Je m'inquiète que mon enfant sera victime d'abus.

1      2      3      4      5

25. Quand je songe à mon enfant dans le contexte de la sexualité, je ne pense qu'à tout ce qui pourrait arriver de mauvais.

1      2      3      4      5

26. J'ai discuté du développement sexuel de mon enfant avec son médecin.

1      2      3      4      5

27. Je suis conscient(e) des problèmes de sexualité qui sont associés au trouble de mon enfant.

1      2      3      4      5

28. Je suis capable de prendre de bonnes décisions concernant les besoins d'éducation sexuelle de mon enfant.

1      2      3      4      5

29. J'ai acquis les connaissances nécessaires pour aider mon enfant dans son développement sexuel et dans son apprentissage de la sexualité.

1      2      3      4      5

30. J'aimerais que mon enfant me pose des questions au sujet de la sexualité et du développement sexuel.

1      2      3      4      5

31. J'aimerais que mon enfant ait des relations sexuelles quand il/elle se sentira prêt(e) et que ce soit sa propre décision.

1      2      3      4      5

32. Je me sens mal à l'aise de parler de questions liées au développement sexuel de mon enfant avec son médecin.

1      2      3      4      5

33. Je sens que je manque vraiment d'expérience pour faire face aux questions liées au développement sexuel de mon enfant.

1      2      3      4      5

## **Échelle adaptée du développement sexuel chez le jeune<sup>17</sup>**

Veillez répondre aux questions suivantes concernant le développement sexuel de votre enfant, son comportement sexuel, ses expériences sexuelles et son éducation sexuelle.

### **Intimité**

**1. Est-ce que votre enfant sait quelles parties du corps sont intimes (privées)?**

\_\_\_\_\_ Pas du tout  
\_\_\_\_\_ Un peu  
\_\_\_\_\_ Oui

**2. Est-ce que votre enfant respecte le droit à l'intimité (vie privée) des autres?**

\_\_\_\_\_ Pas du tout  
\_\_\_\_\_ Un peu  
\_\_\_\_\_ Oui

**3. Est-ce que votre enfant recherche l'intimité? (entourez la bonne réponse) :**

→ Quand votre enfant s'habille/se déshabille

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

→ Quand votre enfant prend un bain ou une douche

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

→ Quand votre enfant est aux toilettes/à la salle de bain

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

→ Quand votre enfant se masturbe

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

→ Quand votre enfant a envie d'être seul(e)

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

---

<sup>17</sup> Adapted from Nichols, S. (2005). *Youth sexuality development scale*®. Used with permission.

**4. Est-ce que votre enfant comprend les règles suivantes concernant l'intimité? (entourez la bonne réponse) :**

→ Toucher les parties intimes de son corps uniquement dans des lieux privés

Pas du tout    Un peu                      Oui

→ Fermer la porte quand on est aux toilettes/dans la salle de bain

Pas du tout    Un peu                      Oui

→ Se déshabiller uniquement quand on est dans un endroit privé

Pas du tout    Un peu                      Oui

→ Baisser son pantalon uniquement dans une salle de bain, aux toilettes ou dans sa propre chambre

Pas du tout    Un peu                      Oui

→ Ne pas se promener tout(e) nu(e) dans la maison

Pas du tout    Un peu                      Oui

→ Frapper à la porte quand une porte est fermée, et attendre que quelqu'un dise qu'on peut rentrer avant d'ouvrir la porte

Pas du tout    Un peu                      Oui

**5. Comment avez-vous appris les règles gouvernant l'intimité à votre enfant? (encerclez toutes les réponses qui s'appliquent) :**

\_\_\_\_\_ En lui fournissant des modèles des comportements appropriés

\_\_\_\_\_ En lui donnant des consignes

\_\_\_\_\_ En lui répétant les consignes

\_\_\_\_\_ En appliquant une discipline à titre de parent

\_\_\_\_\_ En récompensant et en renforçant ses comportements appropriés

\_\_\_\_\_ Par d'autres moyens :

---

Commentaires au sujet de l'intimité dans le cas de votre enfant :
---

## **Comportements sexuels**

**1. Est-ce qu'il arrive à votre enfant de toucher des parties intimes de son corps en public (son pénis ou son vagin, par exemple)?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**2. Est-ce qu'il arrive à votre enfant de se masturber dans des lieux publics?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**3. Est-ce qu'il arrive à votre enfant de se masturber avec des objets insolites ou dangereux (comme des chaussettes ou de la nourriture)?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**4. Est-ce qu'il arrive à votre enfant d'avoir peur de toucher ses parties intimes (comme son pénis ou son vagin) même quand il/elle en a le droit (dans la salle de bain ou pendant sa toilette, par exemple)?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**5. Est-ce qu'il arrive que votre enfant envahisse l'espace privé des autres (en se tenant trop près d'eux, par exemple)?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**6. Est-ce qu'il est arrivé à votre enfant de toucher quelqu'un d'une façon inappropriée (par exemple, en essayant de serrer dans ses bras, d'embrasser ou de toucher les parties intimes de quelqu'un qui ne voulait pas que votre enfant les touche)?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**7. Est-ce qu'il est arrivé à votre enfant de se déshabiller en public dans une situation où c'était inapproprié?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**Si vous avez répondu à la question 7 par l'affirmative, quand est-ce que votre enfant s'est déshabillé en public pour la dernière fois? Quel âge avait votre enfant à ce moment-là?** \_\_\_\_\_

**8. Est-ce que votre enfant a déjà regardé des sites pornographiques à l'Internet?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**9. Est-ce qu'il est arrivé à votre enfant d'avoir des ennuis parce qu'il/elle a parlé de sexualité ou d'activités sexuelles d'une manière inacceptable pour une jeune personne de son âge?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

**10. Est-ce qu'il est arrivé que votre enfant se conduise de façon inappropriée avec quelqu'un pour qui il/elle éprouvait des sentiments romantiques (en leur téléphonant trop souvent ou en les suivant un peu partout à l'école, par exemple)?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

Précisez le comportement inapproprié qu'a manifesté votre enfant :

---

**11. Est-ce que votre enfant manifeste des obsessions sexuelles (exemple : la sexualité est devenue sa seule source d'intérêt et de stimulation - l'enfant est obsédé(e) par les relations sexuelles, ne pense qu'à se trouver un(e) petit(e) ami(e), se masturbe de façon compulsive, a des fantasmes continuels, etc.)?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

Le cas échéant, précisez quelle obsession :

---

**12. Y a-t-il d'autres comportements sexuels qui n'ont pas été cités précédemment mais qui posent un défi?**

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

Précisez quel(s) comportement(s) sexuels :

---

Commentaires au sujet des comportements sexuels de votre enfant :

## Éducation sexuelle

1. Est-ce que votre enfant a reçu le moindre type d'éducation sexuelle?

Non

Oui

Commentaire :

---

---

2. Si vous avez répondu OUI à la question précédente, auprès de qui est-ce que votre enfant a reçu cette éducation sexuelle?

de ma part

à l'école

de la part d'un autre membre de la famille

à l'aide d'images, de vidéos, et par la lecture de livres

auprès de ses pairs, de ses camarades de classe et de ses ami(e)s

dans un contexte thérapeutique (auprès d'un conseiller, par exemple)

dans d'autres circonstances : \_\_\_\_\_

3. Est-ce que cette éducation sexuelle a été utile à votre enfant? (encerclez la bonne réponse)

Pas utile du tout

Un peu utile

Très utile

4. Avez-vous l'intention de permettre à votre enfant de participer au programme d'éducation sexuelle à son école ou à un programme qui se donnerait après l'école? (encerclez la bonne réponse)

Oui, mon enfant y a déjà participé ou il/elle y participe à l'heure actuelle

Oui, je laisserai mon enfant y participer le moment venu

Non, je n'ai pas inscrit mon enfant à ce programme

Non, je ne laisserai pas mon enfant y participer le moment venu

L'école de mon enfant n'offre pas de programme d'éducation sexuelle

5. Est-ce qu'une éducation sexuelle appropriée serait utile à votre enfant? (encerclez la bonne réponse)

Pas utile du tout Un peu utile Très utile

Commentaires au sujet de l'éducation sexuelle de votre enfant :

## **Expériences sexuelles**

**1. Est-ce que votre enfant a manifesté des sentiments romantiques à l'égard de quelqu'un (par exemple : est-ce que votre enfant a dit qu'une fille était jolie/qu'un garçon était mignon)?**

Jamais Rarement Parfois Souvent Je ne sais pas Sans objet

**2. Est-ce que votre enfant est déjà sorti(e) avec une fille/un garçon (pour aller voir un film, pour le bal de fin d'année, etc.)?**

Jamais Rarement Parfois Souvent Je ne sais pas Sans objet

**3. Est-ce que votre enfant a déjà eu un(e) petit(e) ami(e) (quelqu'un avec qui votre enfant est sorti(e) au moins 5 fois)?**

Jamais Rarement Parfois Souvent Je ne sais pas Sans objet

**4. Est-ce que votre enfant a déjà exprimé qu'il/elle ressentait une certaine confusion ou un conflit concernant son identité sexuelle (incertitude d'appartenir au sexe masculin ou féminin, par exemple)?**

Jamais Rarement Parfois Souvent Je ne sais pas Sans objet

**5. Est-ce que votre enfant a déjà manifesté des sentiments romantiques à l'égard de personnes qui sont du même sexe que votre enfant?**

Jamais Rarement Parfois Souvent Je ne sais pas Sans objet

**6. Pour s'assurer de son bon développement, est-ce que votre enfant a subi un examen physique complet auprès d'un médecin, y compris un examen de ses organes sexuels?**

Jamais Rarement Parfois Souvent Je ne sais pas Sans objet

**Si vous avez répondu OUI à la question précédente, ou que vous en avez L'INTENTION, comment avez-vous préparé / allez-vous préparer votre enfant pour ce rendez-vous?**

---

---

---

Commentaires au sujet des expériences sexuelles de votre enfant :

## **Passage progressif à l'âge adulte**

1. Est-ce que votre enfant a déjà exprimé des craintes, des inquiétudes, de l'anxiété ou une nervosité à la perspective de "grandir"?

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

2. Est-ce que votre enfant souhaite fortement ne PAS grandir?

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

3. Est-ce que vous avez observé des changements dans les craintes et inquiétudes que votre enfant a manifestées au moment de la puberté?

Jamais Rarement Parfois Souvent Toujours Je ne sais pas Sans objet

## **Bullying/Harcèlement sexuel**

1. Est-ce que votre enfant a déjà fait l'expérience de *bullying/harcèlement sexuel* (le cas échéant, faites une coche : ✓ ) tel que :

- exposition indécente (quelqu'un a exposé ses parties intimes devant votre enfant)
- propagation de rumeurs sexuelles concernant votre enfant
- moqueries concernant l'orientation sexuelle de votre enfant
- moqueries ou taquineries concernant des parties sexuelles intimes de votre enfant (comme une remarque du genre : Woua! Beaux nichons!)
- gestes ou regards obscènes ou sexuels à l'égard de votre enfant (comme de faire le geste de se masturber)
- commentaires ou blagues à caractère sexuel à l'égard de votre enfant
- appels téléphoniques ou texto de nature sexuelle
- envoi de notes, messages, photos ou images de nature sexuelle que votre enfant ne désire pas recevoir
- emploi d'un terme désobligeant associé à l'orientation sexuelle de votre enfant (comme de se faire appeler "fag", "pédé", "tapette", "pervers", "lesbienne", "gai", "homo", "lesbo")
- vêtements tirés/soulevés d'une façon sexuelle
- taquineries concernant les traits physiques (comme : "Tu es gros et moche")
- frôlement à connotation sexuelle (où une autre personne touche légèrement votre enfant ou passe extrêmement près de votre enfant d'une façon sexuelle)
- touché(e), attrapé(e) ou pincé(e) d'une façon sexuellement intrusive
- forcé(e) d'embrasser un pair
- forcé(e) par un pair d'exécuter un acte sexuel autre que d'embrasser
- espionné(e) quand il/elle s'habille/se déshabille ou se douche à l'école
- messages/graffiti sexuels concernant l'enfant sur les murs des toilettes, au vestiaire ou dans les médias sociaux à l'Internet, etc.
- Autre expérience de bullying sexuel : \_\_\_\_\_
- Autre expérience de bullying sexuel : \_\_\_\_\_

**2. Si vous avez COCHÉ au moins une des déclarations précédentes, avec quelle fréquence ce bullying/harcèlement sexuel se produit-il? :**

- une fois par mois maximum
- quelques fois par mois
- une fois par semaine
- quelques fois par semaine
- presque tous les jours

**3. Si vous avez COCHÉ des déclarations dans la question 1 qui précède, avez-vous essayé de parler de ces problèmes aux responsables de l'école de votre enfant?**

- non
- oui
- pas encore, mais j'en ai l'intention

Commentaires au sujet du passage progressif à l'âge adulte et du bullying/harcèlement sexuel :

### **Renseignements démographiques**

Votre âge : \_\_\_\_\_

Âge de votre enfant : \_\_\_\_\_

Votre sexe : \_\_\_\_\_

Sexe de votre enfant : \_\_\_\_\_

Autres commentaires au sujet de cette étude :

***Veillez retourner ce sondage dûment rempli  
- ainsi que le formulaire de consentement dûment rempli et signé -  
dans l'enveloppe pré-adressée et affranchie  
qui se trouve dans cette trousse de documents.***

***Si vous désirez participer également à l'entrevue  
qui sera effectuée dans le cadre de cette étude,  
veuillez remplir et signer  
le formulaire de consentement à être contacté(e).***

***Je vous remercie de l'intérêt et du temps  
que vous avez généreusement accordés à cette étude.***

## Appendix M: Youth Consent Form and Survey (English)



uOttawa

### YOUTH SURVEY CONSENT FORM

**Title of Study:** Conceptualizations of Sexuality Education for Youth with an Autism Spectrum Disorder

**Main Researcher:** Nathalie A. Gougeon, PhD Candidate, MS Ed, BCBA

#### INTRODUCTION

This study is being done as part of a Doctorate of Philosophy in Education from the University of Ottawa. Please take some time to read and carefully consider the information below before you give your consent to take part in this study. This information will describe the purpose and procedures, as well as the possible risks and benefits of the study. You are encouraged to ask any questions you may have about the study to the main researcher of this study. A copy of this consent form has been included for you to keep. This study will be conducted in both English and French and you will have the choice of which language you would prefer.

#### PURPOSE:

You are invited to participate in a study looking at the sexuality education needs and experiences of youth with high-functioning autism/Asperger syndrome and their families. Some of the questions being asked as part of this study are personal in nature. The survey will ask your opinion about sexuality education for yourself, your sexual behaviours (for example, seeking privacy, touching self and others), positive and negative experiences (for example, dating, sexual bullying, ), and so forth.

#### PROCEDURES

You are being asked to take part in a survey about your experience as a youth with high-functioning autism or Asperger syndrome.

The survey will take about 30 minutes to complete. No one other than the main researcher and/or thesis committee members will have access to this survey. You will have the option to complete the survey in either English or French.

#### POSSIBLE BENEFITS

There are no benefits from participating in this study; if your family is currently on the waitlist for ABA services, participating in this study will **not** change your position on this waitlist. However, this study will give you the chance to express your opinion and to provide the main researcher with important information on how to improve the delivery of sexuality education to youth with autism and their families. We hope that your information will help to develop a sexuality education program in the future, as well as provide information that will eventually improve policies and programs for youth with autism.

#### POSSIBLE RISKS

Because of the sensitive nature of the subject matter, you may feel uncomfortable answering some of the questions. The researcher will try to reduce any potential risks by making sure that all information is kept confidential, whenever possible. If you feel uncomfortable answering any of the questions in this survey, you may choose not to answer them, and if you wish to stop the survey, you are free to do so at any time. If you choose to share personal information that involves illegal or dangerous behaviours (for example, if you were a victim of sexual abuse or bullying), the researcher will be required by law to share this information with proper authorities (for example, the Children's Aid Society or police services). If you share information that may require additional resources, the

researcher will contact you to provide you with information on available resources and/or community agencies that can support this situation.

### **CONFIDENTIALITY**

Unless required by law, all information collected during the study will be kept entirely confidential and will be stored in a secure place at the offices of the Autism Program of Eastern Ontario. The study information will be stored at the Autism Program of Eastern Ontario for 7 years following the end of the study, after which time all raw information we have collected will be destroyed. All information we collect will be password protected and stored on an encrypted USB stick. All computers used for this study will be password protected. Only the above-mentioned researchers will have access to the information. In order to keep your answers anonymous, a unique code will be assigned to all information collected about you. Your code will not be based on any identifying information (date of birth, for example).

### **PARTICIPATION**

Your participation in the study is entirely voluntary. You do not have to participate in this study. You can choose not to answer any of the questions and *you have the right to pull out of the study at any time, without consequence.*

### **RESULTS**

The results of this study will be published in the main researcher's doctoral thesis. Also, the results of this study will be put in a report which will be shared with the people who have an interest in the results, including parents and youth participating in this study, as well as partner agencies. There is also the possibility that research results will be presented at conferences or published in peer-reviewed journals. While the information may also be used in future publications and presentations, it will remain confidential and all survey information will be reported as combined information.

### **CONTACT INFORMATION**

If you have any questions or need more information about the study, please contact:

**Main Researcher, PhD Candidate, MS Ed, BCBA :**

*Nathalie Gougeon, phone number, e-mail address*

The CHEO Research Ethics Board (REB) has approved this study. The REB is a group of individuals from scientific and non-scientific backgrounds who review research study projects. Their goal is to ensure the protection of the rights and welfare of people involved in research. For information regarding patients' rights in research studies, you may contact the Chair of the Research Ethics Board at *phone number*, although this person cannot provide any health-related information about the study.



### YOUTH SURVEY CONSENT FORM

**Title of Study:** Conceptualizations of Sexuality Education for Youth an Autism Spectrum Disorder

**Main Researcher:** Nathalie A. Gougeon, PhD Candidate, MS Ed., BCBA

- I have read or been informed of and I understand the above information. I was able to ask questions and my questions have been fully answered.*
- I have kept a copy of this signed consent form.*
- I would like to receive a summary of the results at the end of the study.*

I \_\_\_\_\_ agree to participate in a survey for this study. *(please print your name)*

Telephone Number: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

\_\_\_\_\_

E-mail Address (optional): \_\_\_\_\_

_____	_____	_____
Study participant's name	Study participant's signature	Date signed

*If the participant is under 16, or if the child is 16 or older but is not able to consent for him/herself, parent must also sign below:*

_____	_____	_____
Parent's name	Parent's signature	Date signed

_____	_____	_____
Investigator's name	Investigator's signature	Date signed

Research ID: \_\_\_\_\_

Do you have a diagnosis of high-functioning autism/Asperger syndrome?

Yes                      No

Are you between the ages of 12 and 18?

Yes                      No

Note: If you have answered NO to any of the above questions, you cannot participate in the study. Thank you for your time.

### **Adapted Youth Sexuality Development Scale<sup>18</sup>**

Please answer the questions below about your sexuality development, behaviour, experiences, and learning.

#### **Privacy**

**1. Do you know which body parts are private?**

\_\_\_\_\_ Not at all  
\_\_\_\_\_ Somewhat  
\_\_\_\_\_ Yes  
\_\_\_\_\_ I don't understand this question

**2. Do you respect other people's privacy?**

\_\_\_\_\_ Not at all  
\_\_\_\_\_ Somewhat  
\_\_\_\_\_ Yes  
\_\_\_\_\_ I don't understand this question

**3. Do you make sure you are in a private place (circle your answer):**

While dressing/undressing

Never Rarely Sometimes Often Always I don't understand this question

When bathing or showering

Never Rarely Sometimes Often Always I don't understand this question

While using the toilet

Never Rarely Sometimes Often Always I don't understand this question

---

<sup>18</sup> Adapted from Nichols, S. (2005). *Youth sexuality development scale*®. Used with permission.

While masturbating (touching your private parts to feel good)

Never Rarely Sometimes Often Always I don't understand this question

When you want to be alone

Never Rarely Sometimes Often Always I don't understand this question

**4. Do you understand the following rules about privacy (circle your answer):**

Touch your own private body parts in private places only

Not at all      Somewhat      Yes      I don't understand this question

Close the bathroom door when you are in the bathroom

Not at all      Somewhat      Yes      I don't understand this question

Take off your clothes only when you are in a private place

Not at all      Somewhat      Yes      I don't understand this question

Undo your pants only in the bathroom, a changing room, or your bedroom

Not at all      Somewhat      Yes      I don't understand this question

Don't walk around the house without any clothes on

Not at all      Somewhat      Yes      I don't understand this question

Knock on closed doors and wait for someone to say it is OK to enter before opening the door

Not at all      Somewhat      Yes      I don't understand this question

**5. How did your parents teach you about rules concerning privacy? (check all that apply)**

They modeled the right behaviours

They provided instructions and directions

They repeated instructions

They used discipline

They rewarded appropriate behaviour

Others: \_\_\_\_\_

I don't understand this question

Do you have any comments to share about privacy:

## **Sexual Behaviours**

**1. Do you ever touch your private body parts (for example, your penis or your vagina) in public?**

Never Rarely Sometimes Often Always I don't understand this question

**2. Do you ever masturbate (touch your private parts to make them feel good) in a public place?**

Never Rarely Sometimes Often Always I don't understand this question

**3. Do you ever masturbate (touch your private parts to make them feel good) with unusual or dangerous objects (for example, socks, food)?**

Never Rarely Sometimes Often Always I don't understand this question

**4. Are you ever afraid to touch your private body parts (for example, your penis or your vagina) when it is OK to do so (when you are using the bathroom, when you are washing yourself)?**

Never Rarely Sometimes Often Always I don't understand this question

**5. Have you ever been told that you were not respecting another person's personal space (for example, someone has told you that you are standing too close to them)?**

Never Rarely Sometimes Often Always I don't understand this question

**6. Have you ever been told that touched another person in an inappropriate way (for example, you got in trouble for trying to hug or kiss or touch someone who did not want you to touch them )?**

Never Rarely Sometimes Often Always I don't understand this question

**7. Have you ever gotten in trouble for taking off your clothes in public when it was not OK to do so?**

Never Rarely Sometimes Often Always I don't understand this question

**If you answered yes, when was the last time you removed your clothes in public?**

---

**8. Have you ever looked at Internet porn sites (Internet sites that show naked people touching their own or other people's private parts)?**

Never Rarely Sometimes Often Always I don't understand this question

**9. Do you ever talk about sex or sexual activities in a way that has gotten you in trouble?**

Never Rarely Sometimes Often Always I don't understand this question

**10. Have you gotten into trouble for the way you acted towards someone that you were romantically interested in (for example, have you called the person you liked more than twice in a day, you followed the person you like around school)?**

Never Rarely Sometimes Often Always I don't understand this question

Please describe the behaviour that got you in trouble:

---

**11. Have you ever developed a sexual obsession (for example, you were obsessed with idea of having sex, obsessed with having a girlfriend or boyfriend, you masturbated more than twice in one day)?**

Never Rarely Sometimes Often Always I don't understand this question

Please describe the sexual obsession:

---

Do you have any comments to share about sexual behaviours:

## **Sexuality Education**

**1. Have you received any type of sexuality education?**

No

Yes

I don't understand this question (if you checked this line, skip to question 4)

**2. If you answered YES, who provided you with the sexuality education?**

you learned it on your own

you learned about it from a teacher at school

you learned about it from another family member

you learned about it through pictures, videos, reading books

you learned about it from peers, classmates, and friends

you learned about it in a therapeutic context (for example, from a counselor)

other: \_\_\_\_\_

**3. Did you find the sexuality education useful ? (circle answer)**

Not at all Useful

Somewhat Useful

Very Useful

**4. Would you like to participate in a sexuality education program through your school or through an after school program?**

I have participated in a sexuality education program already

Yes, I would like to participate in a sexuality education program if one was available

No, I would not want to participate in a sexuality education program if one was available

I don't understand this question

**5. Do you think that sexuality education would be useful for you? (circle answer)**

Not at all useful Somewhat useful Yes very useful I don't understand this question

Do you have any comments to share about sexuality education:

**Sexual Experience**

**1. Have you ever expressed a romantic interest in anyone (for example, said a girl is cute)?**

Never Rarely Sometimes Often Always I don't understand this question

**2. Have you ever gone on a date with someone else (for example, to a movie, to prom)?**

Never Rarely Sometimes Often I don't understand this question

**3. Have you ever had a boyfriend or girlfriend (for example, someone you have dated more than 5 times)?**

Never Rarely Sometimes Often I don't understand this question

**4. Have you ever been confused about your gender identity (for example, feeling like you should be a girl if you are boy or feeling like you be a girl if you are boy)?**

Never Rarely Sometimes Often Always I don't understand this question

**5. Have you ever expressed a romantic interest in a person of the same sex as you (for example, if you are a boy, have you ever wanted to kiss another boy? If you are a girl, have you ever wanted to kiss another girl)**

Never Rarely Sometimes Often Always I don't understand this question

**6. As part of healthy development, have you ever had a complete physical examination by a doctor of your entire body, including your sexual body parts?**

Yes                      No                      I don't understand this question

Do you have any comments to share about sexual experience:

## **Growing Up**

### **1. Are you ever afraid or worried about growing up?**

Never Rarely Sometimes Often Always I don't understand this question

### **2. Do you NOT want grow up?**

Never Rarely Sometimes Often Always I don't understand this question

### **3. Are you afraid or worried about the physical changes that are part of puberty?**

Never Rarely Sometimes Often Always I don't understand this question

## **Bullying**

### **1. Have you ever experienced sexual bullying such as (please check):**

- being "flashed" or "mooned" (someone showing their private parts to you)
- having sexual rumours spread about you
- being teased about your sexual orientation (about liking boys or girls)
- being taunted or teased about sexual body parts (for example, being told "hey, nice boobs")
- sexual gestures or looks (for example, someone staring at your chest if you are girl or staring at your behind in a way that makes you uncomfortable))
- hearing sexual comments or jokes
- getting phone calls or texts of a sexual nature
- being passed unwanted notes, messages, photographs, or pictures about sex
- being called a mean name associated to your sexual orientation (for example, being called "fag", "homo", "dyke", "queer", "gay", "lesbo")
- having your clothes pulled in a sexual way
- being teased about your attractiveness (for example, being told "you're fat and ugly")
- being brushed up against in a sexual way
- being touched, grabbed, or pinched in a physically intrusive sexual way
- being forced to kiss a peer
- being forced by a peer to do something sexual other than kissing
- being spied on while dressing or showering at school
- having sexual messages/graffiti written about you on bathroom walls, the locker room, on the Internet via social media pages, or other places
- Other: \_\_\_\_\_
- Other: \_\_\_\_\_
- I don't understand this question

### **2. If you answered YES to any of the above, how frequently does the sexual bullying occur:**

- once a month or less
- a few times a month
- once a week
- a few times a week
- almost every day

3. If you answered YES to the above questions about sexual bullying, have you brought up these issues with your parents?

\_\_\_\_\_ no

\_\_\_\_\_ yes

\_\_\_\_\_ not yet, but planning to

Do you have any comments to share about growing up and bullying:

### **Demographic Information**

Your age: \_\_\_\_\_

Your gender: \_\_\_\_\_

Any other comments about this survey:

***Please return this completed survey, along with the signed consent form in the self-addressed stamped envelope included in this package.***

***If you are also interested in participating in the interview portion of this study, please also complete and return the Consent to Contact form.***

***Thank you for your time.***

## Appendix N: Youth Consent Form and Survey (French)



uOttawa

### **FORMULAIRE DE CONSENTEMENT À UN SONDAGE À L'INTENTION DES JEUNES PARTICIPANTS**

**Titre de l'étude :** Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

**Chercheur :** Nathalie A. Gougeon, candidate au doctorat, MS Ed, BCBA

#### **INTRODUCTION**

La chercheuse mène cette étude dans le cadre de son doctorat en Éducation (Université d'Ottawa). Nous vous remercions d'avance de prendre le temps de lire les renseignements qui suivent très attentivement avant de consentir à participer à l'étude. Les renseignements ci-dessous expliquent l'objectif de l'étude, son déroulement, ainsi que ses risques et avantages potentiels. Nous vous encourageons à obtenir tout renseignement supplémentaire auprès de la chercheuse. Nous vous remettons une copie de ce formulaire, que vous pourrez conserver. L'étude sera menée en français et en anglais : vous aurez donc le choix d'y participer dans l'une ou l'autre de ces langues.

#### **OBJECTIF DE L'ÉTUDE**

Vous êtes invité(e) à participer à une étude qui examinera les besoins et l'expérience des jeunes atteints d'autisme de haut niveau/du syndrome d'Asperger et de leurs familles dans le domaine de l'éducation à la sexualité. Certaines des questions qui seront posées dans le cadre de cette étude sont de nature personnelle. Dans le sondage, on vous demandera de donner votre opinion concernant votre éducation à la sexualité et de parler de vos comportements sexuels (de votre recherche de l'intimité, de votre habitude de vous toucher ou de toucher d'autres personnes, par exemple), de vos expériences positives et négatives (de vos relations intimes ou de bullying/harcèlement sexuel, par exemple), etc.

#### **DÉROULEMENT DE L'ÉTUDE**

Nous vous invitons à participer à un sondage où vous pourrez parler de votre expérience en tant que jeune avec l'autisme de haut niveau/le syndrome d'Asperger.

Le sondage durera environ 30 minutes. Personne n'aura accès à vos réponses au sondage en dehors de la chercheuse et des membres de son comité de thèse. Vous aurez le choix de faire le sondage en français ou en anglais.

#### **AVANTAGES POTENTIELS**

La participation à cette étude ne présente aucun avantage pour les participants; si votre famille est actuellement sur une liste d'attente pour recevoir des services d'ACA, votre participation à cette étude ne changera **pas** votre position sur cette liste. Toutefois, cette étude vous donnera la possibilité d'exprimer votre point de vue et de fournir à la chercheuse des informations importantes concernant les moyens d'améliorer la prestation de l'éducation à la sexualité auprès des jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger et de leurs familles. Notre espoir est que les informations que vous nous fournirez nous permettront d'élaborer un curriculum pertinent et, par la suite, d'améliorer les politiques et les programmes pour les jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger.

#### **RISQUES POTENTIELS**

Étant donné la nature délicate du sujet, il est possible que vous vous sentiez mal à l'aise de répondre à certaines des questions. La chercheuse s'efforcera de réduire ce risque potentiel en s'assurant, dans la mesure du possible, que vos informations demeureront confidentielles. La chercheuse fera également tout son possible pour que vous vous sentiez à l'aise tout au long du sondage. Si, toutefois, vous vous sentiez mal à l'aise à n'importe quel moment au cours du sondage, vous serez entièrement libre de sauter une question; vous êtes également entièrement libre de vous retirer de ce sondage à n'importe quel moment. Si vous décidez de partager avec la chercheuse des informations personnelles qui concernent des comportements dangereux ou illégaux (au cas, par exemple, où vous avez été victime d'abus sexuels ou de harcèlement), la chercheuse sera dans l'obligation légale de faire part de ces informations aux autorités pertinentes (Société d'aide à l'enfance ou services de police, par exemple). Si vous partagez avec la chercheuse des informations qui pourraient exiger des ressources supplémentaires, la chercheuse vous fournira des renseignements sur les ressources disponibles ou les agences communautaires qui pourraient vous apporter un soutien dans ces situations.

### **CONFIDENTIALITÉ**

À moins que la loi ne l'exige, toutes les informations qui seront recueillies au cours de cette étude demeureront strictement confidentielles et elles seront conservées en lieu sûr aux bureaux du Programme d'autisme de l'Est de l'Ontario. Les informations recueillies dans cette étude seront conservées aux bureaux du Programme d'autisme de l'Est de l'Ontario pendant une période de 7 ans suivant la fin de l'étude; après cette période, toutes les informations brutes, transcriptions et notes de terrain seront déchiquetées et tous les enregistrements seront effacés. Toutes les transcriptions et notes de terrain et tous les fichiers audio seront protégés par un mot de passe et conservés sur une clé USB chiffrée. Tous les ordinateurs sur lesquels des informations seront conservées seront protégés par un mot de passe. Seule la chercheuse citée précédemment aura accès à ces informations. Pour que vos réponses demeurent anonymes, un code unique sera donné à toutes les informations qui auront été recueillies à votre sujet. Votre code n'aura aucun rapport avec les renseignements qui permettraient de connaître votre identité (tels que date de naissance ou autre).

### **PARTICIPATION**

Votre participation à cette étude est absolument volontaire. Vous n'êtes aucunement obligé(e) de participer. Vous avez également le droit de refuser de répondre à n'importe quelle question et *vous avez le droit de vous retirer de l'étude à n'importe quel moment sans aucune conséquence.*

### **RÉSULTATS**

Les résultats de cette étude seront publiés dans la thèse de doctorat de la chercheuse. De plus, ces résultats seront résumés dans un rapport qui sera remis aux personnes qui s'intéressent aux constatations de l'étude, y compris aux parents et aux jeunes qui auront participé à cette étude et aux agences qui travaillent en partenariat avec le Programme d'autisme de l'Est de l'Ontario. Il est possible également que les résultats de cette étude soient présentés à des conférences ou publiés dans des revues scientifiques à comité de lecture. Si les informations recueillies dans cette étude sont utilisées dans des publications ou pour des présentations professionnelles, elles demeureront totalement confidentielles et seront présentées dans leur ensemble.

### **POUR TOUT RENSEIGNEMENT SUPPLÉMENTAIRE**

Si vous désirez de plus amples renseignements concernant cette étude, n'hésitez pas à contacter la chercheuse :

**Nathalie Gougeon - candidate au doctorat, MS Ed, BCBA :**

*Tél. : numéro de téléphone, adresse électronique*

Cette étude a reçu l'approbation du Comité d'éthique de la recherche du CHEO. Le Comité regroupe des scientifiques et des non-scientifiques dont la mission est d'évaluer les projets de recherche qui leur sont soumis. Ils ont la responsabilité d'assurer la protection des droits et du bien-être des personnes qui participent à des études de recherche. Pour tout renseignement concernant les droits des participants à une étude de recherche, vous pouvez contacter le président du Comité d'éthique de la recherche du CHEO, au *numéro de téléphone*. Veuillez noter, toutefois, que cette personne ne peut fournir aucun renseignement de santé concernant cette étude.



## FORMULAIRE DE CONSENTEMENT À UN SONDAGE POUR LES JEUNES PARTICIPANTS

**Titre de l'étude :** Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

**Chercheure :** Nathalie A. Gougeon, candidate au doctorat, MS Ed., BCBA

*J'ai lu les renseignements qui précèdent ou on m'en a informé(e), et je comprends ces renseignements. On m'a donné la possibilité de poser des questions et on a répondu à mes questions de façon satisfaisante.*

*On m'a remis une copie de ce formulaire de consentement dûment rempli et signé.*

*J'aimerais recevoir un résumé des résultats à la fin de l'étude.*

Je soussigné(e) \_\_\_\_\_ (votre nom en lettres moulées) accepte de participer à un sondage dans le cadre de cette étude.

N° de téléphone : \_\_\_\_\_

Adresse postale : \_\_\_\_\_

Adresse courriel (facultatif) : \_\_\_\_\_

\_\_\_\_\_  
Nom du participant

\_\_\_\_\_  
Signature du participant

\_\_\_\_\_  
Date de signature

*Si le jeune participant a moins de 16 ans, ou que le jeune participant a entre 16 et 18 ans mais n'est pas en mesure de donner son consentement, un parent doit également signer ci-dessous.*

\_\_\_\_\_  
Nom du parent

\_\_\_\_\_  
Signature du parent

\_\_\_\_\_  
Date de signature

\_\_\_\_\_  
Nom de la chercheure

\_\_\_\_\_  
Signature de la chercheure

\_\_\_\_\_  
Date de signature

Code de recherche : \_\_\_\_\_

Est-ce que vous avez reçu un diagnostic d'autisme de haut niveau/syndrome d'Asperger?

Oui Non

Est-ce que vous avez entre 12 et 18 ans?

Oui Non

Note : Si vous avez répondu NON à l'une des questions qui précèdent, vous ne pouvez pas participer à cette étude. Nous vous remercions toutefois que votre intérêt pour cette recherche.

### **Échelle adaptée du développement sexuel chez le jeune<sup>19</sup>**

Veuillez répondre aux questions suivantes concernant votre développement sexuel, votre comportement sexuel, vos expériences sexuelles et votre apprentissage de la sexualité.

#### **Intimité**

**1. Est-ce que tu sais quelles parties du corps sont intimes (privées)?**

\_\_\_\_\_ Pas du tout  
\_\_\_\_\_ Un peu  
\_\_\_\_\_ Oui  
\_\_\_\_\_ Je ne comprends pas cette question

**2. Est-ce que tu respectes le droit à l'intimité (à la vie privée) des autres?**

\_\_\_\_\_ Pas du tout  
\_\_\_\_\_ Un peu  
\_\_\_\_\_ Oui  
\_\_\_\_\_ Je ne comprends pas cette question

**3. Est-ce que tu t'assures d'être dans un endroit privé quand... (entoure ta réponse)? :**

→ Quand tu t'habilles ou que tu te déshabilles

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

→ Quand tu prends un bain ou une douche

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

→ Quand tu es aux toilettes ou dans la salle de bain

<sup>19</sup> Adapted from Nichols, S. (2005). *Youth sexuality development scale*®. Used with permission.

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

→ Quand tu te masturbes (quand tu touches tes parties intimes parce que c'est agréable)

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

→ Quand tu as envie d'être seul(e)

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**4. Est-ce que tu comprends les règles suivantes concernant l'intimité (la vie privée)? (entoure ta réponse) :**

→ Il ne faut toucher les parties intimes de son corps que dans des lieux privés

Pas du tout Un peu Oui Je ne comprends pas cette question

→ Il faut fermer la porte quand on est aux toilettes/dans la salle de bain

Pas du tout Un peu Oui Je ne comprends pas cette question

→ Il ne faut se déshabiller que quand on est dans un endroit privé

Pas du tout Un peu Oui Je ne comprends pas cette question

→ On ne peut baisser son pantalon que dans une salle de bain, aux toilettes ou dans sa propre chambre

Pas du tout Un peu Oui Je ne comprends pas cette question

→ Il ne faut pas se promener tout(e) nu(e) dans la maison

Pas du tout Un peu Oui Je ne comprends pas cette question

→ Il faut frapper, quand une porte est fermée, et attendre que quelqu'un dise qu'on peut rentrer avant d'ouvrir la porte

Pas du tout Un peu Oui Je ne comprends pas cette question

**5. Comment est-ce que tes parents t'ont appris les règles qui concernent l'intimité (la vie privée)? (Fais une coche ✓ devant toutes les réponses qui s'appliquent)**

\_\_\_\_\_ Ils m'ont donné des modèles des bons comportements

\_\_\_\_\_ Ils m'ont donné des consignes

\_\_\_\_\_ Ils m'ont répété les consignes

\_\_\_\_\_ Ils ont appliqué une discipline

\_\_\_\_\_ Ils m'ont récompensé(e) quand j'avais un bon comportement

\_\_\_\_\_ Par d'autres moyens : \_\_\_\_\_  
\_\_\_\_\_ Je ne comprends pas cette question

Est-ce que tu as des commentaires au sujet de l'intimité?

### **Comportements sexuels**

**1. Est-ce qu'il t'arrive de toucher des parties intimes de ton corps en public (ton pénis ou ton vagin, par exemple)?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**2. Est-ce qu'il t'arrive de te masturber (de toucher tes parties intimes parce que c'est agréable) dans des lieux publics?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**3. Est-ce qu'il t'arrive de te masturber (de toucher tes parties intimes parce que c'est agréable) avec des objets insolites ou dangereux (comme des chaussettes ou de la nourriture)?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**4. Est-ce qu'il t'arrive d'avoir peur de toucher tes parties intimes (comme ton pénis ou ton vagin) même quand tu en as le droit (quand tu es dans la salle de bain ou que tu te laves, par exemple)?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**5. Est-ce qu'on t'a parfois dit que tu ne respectais pas l'espace privé d'une autre personne (qu'on te dise, par exemple, que tu te tenais trop près de quelqu'un)?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**6. Est-ce qu'on t'a parfois dit que tu avais touché quelqu'un d'une façon inappropriée (par exemple, tu as eu des ennuis parce que tu as voulu serrer quelqu'un dans tes bras, ou l'embrasser, ou toucher quelqu'un qui ne voulait pas que tu les touches)?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**7. Est-ce qu'il t'est arrivé d'avoir des ennuis parce que tu t'es déshabillé en public dans une situation où c'était inapproprié?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**Si tu as répondu à la question 7 par l'affirmative, quand est-ce que tu t'es déshabillé en public pour la dernière fois?**

**8. Est-ce que tu as déjà regardé des sites pornographiques à l'Internet (des sites internet où on voit des gens nus qui se touchent ou qui touchent les parties intimes d'autres personnes)?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**9. Est-ce qu'il t'est arrivé d'avoir des ennuis parce que tu as parlé de sexualité ou d'activités sexuelles d'une manière qui a été jugée inacceptable?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

**10. Est-ce qu'il t'est arrivé d'avoir des ennuis parce que t'es conduit(e) de façon inappropriée avec quelqu'un pour qui tu éprouvais des sentiments romantiques (en leur téléphonant trop souvent ou en les suivant un peu partout à l'école, par exemple)?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

Si c'est le cas, décris le comportement qui t'a causé des ennuis :

---

**11. Est-ce qu'il t'est arrivé d'avoir des obsessions sexuelles (par exemple : est-ce qu'il t'est arrivé d'être obsédé(e) à l'idée d'avoir des relations sexuelles, obsédé(e) à l'idée de te trouver un(e) petit(e) ami(e), de te masturber plus de deux fois par jour, etc.)?**

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

Si c'est le cas, décris cette obsession sexuelle :

---

---

Est-ce que tu as des commentaires au sujet des comportements sexuels?

## Éducation sexuelle

(Fais une coche ✓ devant tes réponses)

**1. Est-ce que tu as reçu le moindre type d'éducation sexuelle?**

\_\_\_\_\_ Non

\_\_\_\_\_ Oui

\_\_\_\_\_ Je ne comprends pas cette question (si tu as fait une coche ✓ ici ou que tu as répondu *Non*, passe directement à la question n° 4 ci-dessous)

**2. Si tu as répondu OUI à la question précédente, auprès de qui est-ce que tu as reçu cette éducation sexuelle?**

\_\_\_\_\_ J'ai appris tout(e) seul(e)

\_\_\_\_\_ J'ai appris auprès d'un(e) enseignant(e) à l'école

\_\_\_\_\_ J'ai appris auprès d'un membre de ma famille

\_\_\_\_\_ J'ai appris à l'aide d'images, de vidéos, et en lisant des livres

\_\_\_\_\_ J'ai appris auprès de mes pairs, de mes camarades de classe et de mes ami(e)s

\_\_\_\_\_ J'ai appris dans un contexte thérapeutique (auprès d'un conseiller, par exemple)

\_\_\_\_\_ J'ai appris dans d'autres circonstances : \_\_\_\_\_

**3. Est-ce que cette éducation sexuelle t'a été utile? (encercle ta réponse)**

Pas utile du tout      Un peu utile      Très utile

**4. Est-ce que tu aimerais participer à un programme d'éducation sexuelle à l'école ou à un programme qui se donnerait après l'école?**

(Fais une coche ✓ devant tes réponses)

\_\_\_\_\_ J'ai déjà participé / ou je participe actuellement à un programme d'éducation sexuelle

\_\_\_\_\_ Oui, j'aimerais participer à un programme d'éducation sexuelle s'il en existait un

\_\_\_\_\_ Non, je n'aimerais pas participer à un programme d'éducation sexuelle s'il en existait

\_\_\_\_\_ Je ne comprends pas cette question

**5. Est-ce que tu penses qu'une éducation sexuelle te serait utile? (encercle ta réponse)**

Pas utile du tout      Un peu utile      Oui, très utile      Je ne comprends pas cette question

Est-ce que tu as des commentaires au sujet de l'éducation sexuelle?

## **Expériences sexuelles**

**1. Est-ce que tu as déjà ressenti des sentiments romantiques pour quelqu'un (par exemple : est-ce qu'il t'est arrivé de penser qu'une fille était jolie/qu'un garçon était mignon)?**

Jamais Rarement Parfois Souvent Je ne comprends pas cette question

**2. Est-ce que tu es déjà sorti(e) avec une fille/un garçon (pour aller voir un film, pour le bal de fin d'année, etc.)?**

Jamais Rarement Parfois Souvent Je ne comprends pas cette question

**3. Est-ce que tu as déjà eu un(e) petit(e) ami(e) (quelqu'un avec qui tu es sorti(e) au moins 5 fois)?**

Jamais Rarement Parfois Souvent Je ne comprends pas cette question

**4. Est-ce qu'il t'arrive de ressentir une certaine confusion concernant ton identité sexuelle (par exemple : est-ce qu'il t'est arrivé de penser que tu aimerais mieux être une fille au lieu d'un garçon / ou un garçon au lieu d'une fille)?**

Jamais Rarement Parfois Souvent Je ne comprends pas cette question

**5. Est-ce qu'il t'est arrivé d'exprimer des sentiments romantiques à quelqu'un du même sexe que toi (par exemple : si tu es un garçon, est-ce qu'il t'est arrivé d'avoir envie d'embrasser un autre garçon? / si tu es une fille, est-ce qu'il t'est arrivé d'avoir envie d'embrasser une autre fille)?**

Jamais Rarement Parfois Souvent Je ne comprends pas cette question

**6. Pour t'assurer de ton bon développement, est-ce que tu as déjà subi un examen physique complet auprès d'un médecin, y compris un examen de tes organes sexuels?**

Oui

Non

Je ne comprends pas cette question

Est-ce que tu as des commentaires au sujet de tes expériences sexuelles?

## Passage progressif à l'âge adulte

### 1. Est-ce qu'il t'arrive d'avoir peur ou de t'inquiéter à l'idée de « grandir »?

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

### 2. Est-ce que tu souhaites fortement ne PAS grandir?

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

### 3. Est-ce que les changements physiques qui surviennent à la puberté te font peur ou t'inquiètent?

Jamais Rarement Parfois Souvent Toujours Je ne comprends pas cette question

## Bullying/Harcèlement sexuel

### 1. Est-ce qu'il t'est arrivé de faire l'expérience de *bullying/harcèlement sexuel* (fais une coche ✓ ) tel que :

- exposition indécente (quelqu'un t'a montré ses parties intimes)
- propagation de rumeurs sexuelles à ton sujet
- moqueries concernant ton orientation sexuelle (concernant le fait que tu aimes les garçons ou que tu aimes les filles)
- moqueries ou taquineries concernant certaines de tes parties sexuelles intimes (comme une remarque du genre : « Woua! Beaux nichons! »)
- gestes ou regards à connotation sexuelle (exemple, si tu es une fille : quelqu'un qui regarde intensément ta poitrine ou tes fesses d'une façon qui te met mal à l'aise)
- commentaires ou blagues à caractère sexuel
- appels téléphoniques ou texto de nature sexuelle
- envoi de notes, messages, photos ou images - concernant le sexe - que tu ne voulais pas recevoir
- emploi de termes méchants à ton égard, associés à ton orientation sexuelle (comme de te faire appeler "fag", "gai", "homo", "lesbo")
- vêtements tirés/soulevés d'une façon sexuelle
- taquineries concernant tes traits physiques (comme de te faire dire : "Tu es gros et moche")
- frôlement à connotation sexuelle (où une autre personne te touche légèrement ou passe extrêmement près de toi d'une façon sexuelle)
- touché(e), attrapé(e) ou pincé(e) d'une façon sexuellement intrusive
- forcé(e) d'embrasser un pair
- forcé(e) par un pair d'exécuter un acte sexuel autre que d'embrasser
- espionné(e) quand tu t'habilles/te déshabilles ou que tu te douches à l'école
- messages/graffiti sexuels à ton sujet sur les murs des toilettes, au vestiaire ou dans les médias sociaux à l'Internet, etc.
- Autre expérience de bullying sexuel : \_\_\_\_\_
- Autre expérience de bullying sexuel : \_\_\_\_\_
- Je ne comprends pas cette question

### 2. Si tu as COCHÉ ✓ au moins une des déclarations précédentes, avec quelle fréquence ce bullying/harcèlement sexuel se produit-il? :

- une fois par mois maximum
- quelques fois par mois

- \_\_\_\_\_ une fois par semaine
- \_\_\_\_\_ quelques fois par semaine
- \_\_\_\_\_ presque tous les jours

**3. Si tu as COCHÉ ✓ des déclarations dans les questions 1 & 2 qui précèdent, as-tu essayé de parler de ces problèmes à tes parents?**

- \_\_\_\_\_ non
- \_\_\_\_\_ oui
- \_\_\_\_\_ pas encore, mais je vais le faire

Est-ce que tu as des commentaires au sujet du passage progressif à l'âge adulte et du bullying sexuel?

### **Renseignements démographiques**

Ton âge : \_\_\_\_\_

Ton sexe : \_\_\_\_\_

As-tu d'autres commentaires au sujet de cette étude?

***Merci d'avance de retourner ce sondage dûment rempli ainsi que le formulaire de consentement signé dans l'enveloppe pré-adressée et affranchie qui se trouve dans cette trousse de documents.***

***Si tu désires participer également à l'entrevue qui sera effectuée dans le cadre de cette étude, tu dois remplir et signer le formulaire de consentement à être contacté(e).***

***Merci de tout le temps que tu m'as généreusement accordé !***

## Appendix O: Caregiver Consent Form and Interview Rubric (English)



### **PARENT/CAREGIVER INTERVIEW CONSENT FORM**

**Title of Study:** Conceptualizations of Sexuality Education for Youth with an Autism Spectrum Disorder

**Main Researcher :** Nathalie A. Gougeon, PhD Candidate, MS Ed, BCBA

#### **INTRODUCTION**

This study is being conducted as part of a Doctorate of Philosophy in Education from the University of Ottawa. Please take a moment to read and carefully consider the information below before you give your consent to take part in this study. This information will describe the purpose and procedures as well as the possible risks and benefits of the study. You are encouraged to ask any questions you may have about the study to the main researcher of this study. If you agree to participate in this study, we will give you a copy of this consent form to keep. This study will be conducted in both English and French and you will have the choice of which language you would prefer.

#### **PURPOSE:**

You are invited to participate in a study looking at the sexuality education needs and experiences of youth with high-functioning autism/Asperger syndrome and their families. Some of the questions being asked as part of this study are personal in nature. The interview will ask your opinion related to sexuality education, what topics should be covered as part of sexuality education, who should be responsible for providing it, and so forth.

#### **PROCEDURES**

You are being asked to take part in an interview about your experience as a parent of a child with high-functioning autism/Asperger syndrome.

The interview will take approximately 30 minutes to complete. The interview will take place either in person at your home or at an office of the Autism Program of Eastern Ontario and will be audio taped. The purpose of audio taping is to assist the researcher in transcribing your feedback with accuracy and in its entirety. No one other than the main researcher and/or thesis committee members will have access to these recordings/transcriptions. You will have the option to complete the interview in either English or French.

#### **POSSIBLE BENEFITS**

There are no benefits from participating in this study; if your family is currently on the waitlist for ABA services, participating in this study will **not** change your position on this waitlist. However, this study will give you the opportunity to express your opinion and to provide the main researcher with important information on how to improve the delivery of sexuality education to youth with autism and their families. We hope that your information will help to develop curriculum in the future, as well as provide information that will eventually improve policies and programs for youth with autism.

#### **POSSIBLE RISKS**

Because of the sensitive nature of the subject matter, you may feel uncomfortable answering some of the questions. The researcher will try to reduce any potential risks by making sure that all information is kept confidential, whenever possible. Every effort will be made to make sure that you are comfortable throughout the entire interview. If you feel uncomfortable during the interview and wish to stop, you are free to do so at any time. If you choose to share personal information that involves illegal or dangerous behaviours (for example, if your child was a victim of

sexual abuse or bullying), the researcher will be required by law to share this information with proper authorities (for example, the Children's Aid Society or police services). If you share information that may require additional resources, the researcher will provide you with information on available resources and/or community agencies that can support this situation.

### **CONFIDENTIALITY**

Unless required by law, all information collected during the study will be kept entirely confidential and will be stored in a secure location at the offices of the Autism Program of Eastern Ontario. The study information will be stored at the Autism Program of Eastern Ontario for 7 years following the end of the study, after which time all raw information, transcripts and field notes will be shredded and audio recordings will be erased. All transcripts, field notes and audio files will be password protected and stored on an encrypted USB stick. All computers on which information will be stored will be password protected. Only the above-mentioned researchers will have access to the information. In order to keep your answers anonymous, a unique code will be assigned to all information collected about you. Your code will not be based on any identifying information (date of birth, for example).

### **PARTICIPATION**

Your participation in the study is entirely voluntary. You are under no obligation to participate. You can decline to answer any questions and *you have the right to withdraw from the study at any time, without consequence.*

### **RESULTS**

The results of this study will be published in the main researcher's doctoral thesis. In addition, the results of this study will be summarized in a report which will be shared with the individuals who have an interest in the results, including parents and youth participating in this study, as well as partner agencies. There is also the possibility that research results will be presented at conferences or published in peer-reviewed journals. While the information may also be used in future publications and presentations, it will remain confidential and all survey information will be reported as combined information.

### **CONTACT INFORMATION**

Should you have any questions or require more information about the study, please contact:

**Main Researcher, PhD Candidate, MS Ed, BCBA :**

*Nathalie Gougeon, phone number, e-mail address*

The CHEO Research Ethics Board (REB) has approved this study. The REB is a group of individuals from scientific and non-scientific backgrounds who review research study projects. Their goal is to ensure the protection of the rights and welfare of people involved in research. For information regarding patients' rights in research studies, you may contact the Chair of the Research Ethics Board at *phone number*, although this person cannot provide any health-related information about the study.



**PARENT/CAREGIVER INTERVIEW CONSENT FORM**

**Title of Study:** Conceptualizations of Sexuality Education for Youth an Autism Spectrum Disorder

**Principal Investigators:** Nathalie A. Gougeon, PhD Candidate, MS Ed., BCBA

- I have read and /or been informed of and I understand the above information. I have had the opportunity to ask questions and my questions have been addressed to my satisfaction.*
- I have been given a copy of this signed consent form.*
- I would like to receive a summary of the results at the end of the study.*

I \_\_\_\_\_ agree to participate in an **interview** for this study. I understand that my  
*(please print your name)*

interview will be audiotaped and I understand that I may be quoted. If I am quoted, all personally identifying information will be removed.

Telephone Number: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

\_\_\_\_\_

E-mail Address (optional): \_\_\_\_\_

\_\_\_\_\_  
Participant's name

\_\_\_\_\_  
Participant's signature

Date signed

\_\_\_\_\_  
Investigator's name

\_\_\_\_\_  
Investigator's signature

Date signed

## Interview Guide for Parents/Caregivers

Research ID: \_\_\_\_\_

- Thank participant for agreeing to interview.
- Review consent form and interview process and duration, obtain one copy of consent form and give one copy to participant.
- Obtain permission for audio recording of interview.

### Themes and possible questions:

(note: these questions are meant to ensure that all themes are covered during the interview. The interviewer should elaborate on topics raised by the interviewee by asking follow-up questions, requesting an elaboration, etc.).

Thank you for agreeing to speak with us today regarding sexuality education for your child. We are conducting research on sexuality education for youth with high-functioning autism/Asperger syndrome. An outcome of this project will be a report summarizing key findings and recommendations taken from the study. This report will be shared with study participants and will be available at the end of this project.

With your permission, we would like to ask you about your views and experience as a parent of a child with high-functioning autism/Asperger syndrome with regards to sexuality education.

Note: Interviewer should specify when saying ‘autism’ in the context of this interview, it will be in reference to ‘high-functioning autism/Asperger syndrome’.

### PART I:

- 1. (Q1) My first question has to do with what ‘sexuality education’ means. In your opinion, what should ‘sexuality education’ encompass for your child?**

Follow-up questions:

(Q1B-C) 1.a. What are some of the key components or topics that should be covered that are specific to the needs of your child?

(Q1B-C) 1.b. Are there any other components or topics you feel are essential to meet the needs of your child?

- 2. (Q1B-C) Are there any components or topics that you feel should not be part of ‘sexuality education’ for your child?**

Follow-up questions:

(Q1B-C) 2.a. Are there any other components or topics you feel should not be part of ‘sexuality education’ for your child?

- 3. (Q1A-P) How do you think sexuality education should be presented?**

Follow-up questions:

(Q1A-P) 3.a. What modality/teaching approaches would best serve your child's strengths? Your child's needs?

(Q1A-P) 3.b. Group format or individual? Mixed gender or segregated? Visual components or oral? Interactive? Any particular approach?

**4. (Q1A-R) Who do you think should be responsible for providing sexuality education to your child? Why?**

Follow-up questions:

(Q1A-R/Q3A-SS/Q3B-SB) 4.a. Do you feel that the person(s) you have identified is well-prepared to provide sexuality education to your child? Why or why not?

(Q1A-R) 4.b. Is there anyone else you think should be responsible? Why?

(Q1A-R/Q3A-SS/Q3B-SB) 4.c. Do you feel that the person(s) you have identified is well-prepared to provide sexuality education to your child? Why or why not?

**PART II:**

**5. (Q1) Has your child received sexuality education?**

Follow-up questions:

(Q1A-R) 5.a. Who provided it?

(Q1A-R/Q3A-SS/Q3B-SB) 5.b. Did it meet your child's learning needs?

5.c. Why or why not?

**6. (Q3B-IB/Q3B-SB) In your opinion, what are the barriers or obstacles to providing/accessing appropriate sexuality education for your child?**

Follow-up questions:

(Q3B-IB/Q3B-SB) 6.a. Why do you think these barriers/obstacles exist?

(Q3B-IB/Q3B-SB) 6.b. Are there any other barriers/obstacles you can think of?

(Q3B-IB/Q3B-SB) 6.c. Why do you think these barriers/obstacles exist?

**7. (Q3B-IB/Q3B-SB) When do these barriers/obstacles arise?**

Follow-up question:

(Q3B-IB/Q3B-SB) 7.a. Why do you think these barriers/obstacles come up at this time?

**8. (Q3B-IB/Q3B-SB) In what ways do you feel these barriers/obstacles impact the delivery of sexuality education for your child?**

Follow-up question:

(Q3B-IB/Q3B-SB) 8.a. Are there other ways you feel these barriers/obstacles impact the delivery of sexuality education for your child?

**9. (Q3A-IS/Q3A-SS) In your opinion, what are the supports that allow for the delivery of sexuality education for your child?**

Follow-up questions:

(Q3A-IS/Q3A-SS) 9.a. Why do you think these supports exist?

(Q3A-IS/Q3A-SS) 9.b. Are there any other supports you can think of?

(Q3A-IS/Q3A-SS) 9.c. Why do you think these supports exist?

**10. (Q3A-IS/Q3A-SS) When do these supports arise?**

Follow-up question:

(Q3A-IS/Q3A-SS) 10.a. Why do you think these supports come up at this time?

**11. (Q3A-IS/Q3A-SS) In what ways do you feel these supports impact the delivery of sexuality education for your child?**

Follow-up question:

(Q3A-IS/Q3A-SS) 11.a. Are there other ways you feel these supports impact the delivery of sexuality education for your child?

**PART III:**

**12. (Q1A-P) At what age will you consider your child to be an adult?**

**13. (Q3A-SS/Q3B-SB) What do you see for your child at this age/when he/she is an adult?**

**PART IV:**

**14. (Q2A/Q2B/Q3A-SS/Q3B-SB) Are you aware of any sexuality education programs or resources that can be used with your child? What are they?**

**15. (Q2A/Q2B/Q3A-SS) Have they been beneficial to your child's learning? In what ways?**

**16. (Q2A/Q2B/Q3B-SB) What was missing from these programs or resources?**

**PART V:**

- 17. Are there any additional questions you think we should have asked you during this interview?**
- 18. Do you have any comments you would like to share about this study (*e.g., strengths, weaknesses, suggestions, preferred format for dissemination of findings*)?**

Thank you for taking the time to speak with me today. I appreciate you assisting me with my research project on sexuality education for youth with autism.

## Appendix P: Caregiver Consent Form and Interview Rubric (French)



uOttawa

### **FORMULAIRE DE CONSENTEMENT À UNE ENTREVUE À L'INTENTION DES PARENTS/RESPONSABLES**

**Titre de l'étude :** Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

**Chercheur :** Nathalie A. Gougeon, candidate au doctorat, MS Ed, BCBA

#### **INTRODUCTION**

La chercheuse mène cette étude dans le cadre de son doctorat en Éducation (Université d'Ottawa). Nous vous remercions d'avance de prendre le temps de lire les renseignements qui suivent très attentivement avant de consentir à participer à l'étude. Les renseignements ci-dessous expliquent l'objectif de l'étude, son déroulement, ainsi que ses risques et avantages potentiels. Nous vous encourageons à obtenir tout renseignement supplémentaire auprès de la chercheuse. Si vous acceptez de participer à cette étude, nous vous remettrons une copie de ce formulaire, que vous pourrez conserver. L'étude sera menée en français et en anglais : vous aurez donc le choix d'y participer dans l'une ou l'autre de ces langues.

#### **OBJECTIF DE L'ÉTUDE**

Vous êtes invité(e) à participer à une étude qui examinera les besoins et l'expérience des jeunes atteints d'autisme de haut niveau/du syndrome d'Asperger et de leurs familles dans le domaine de l'éducation à la sexualité. Certaines des questions qui seront posées dans le cadre de cette étude sont de nature personnelle. Dans l'entrevue, on vous demandera de donner votre opinion concernant l'éducation à la sexualité, concernant quels sujets devraient être abordés dans l'éducation à la sexualité, concernant qui devrait être responsable de l'éducation à la sexualité, etc.

#### **DÉROULEMENT DE L'ÉTUDE**

Nous vous invitons à participer à une entrevue où vous pourrez parler de votre expérience à titre de parent/responsable d'un jeune qui présente l'autisme de haut niveau/le syndrome d'Asperger.

L'entrevue durera environ 30 minutes. Elle sera effectuée en personne, soit chez vous, soit à l'un des bureaux du Programme d'autisme de l'Est de l'Ontario. Toutes les entrevues seront enregistrées, afin d'aider la chercheuse à faire une transcription exacte et complète des déclarations des participants. Personne n'aura accès aux déclarations enregistrées/transcriptions en dehors de la chercheuse et des membres de son comité de thèse. Vous aurez le choix de faire l'entrevue en français ou en anglais.

#### **AVANTAGES POTENTIELS**

La participation à cette étude ne présente aucun avantage pour les participants; si votre famille est actuellement sur une liste d'attente pour recevoir des services d'ACA, votre participation à cette étude ne changera **pas** votre position sur cette liste. Toutefois, cette étude vous donnera la possibilité d'exprimer votre point de vue et de fournir à la chercheuse des informations importantes concernant les moyens d'améliorer la prestation de l'éducation à la sexualité auprès des jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger et de leurs familles. Notre espoir est que les informations que vous nous fournirez nous permettront d'élaborer un curriculum pertinent et, par la suite, d'améliorer les politiques et les programmes pour les jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger.

### **RISQUES POTENTIELS**

Étant donné la nature délicate du sujet, il est possible que vous vous sentiez mal à l'aise de répondre à certaines des questions. La chercheuse s'efforcera de réduire ce risque potentiel en s'assurant, dans la mesure du possible, que vos informations demeureront confidentielles. La chercheuse fera également tout son possible pour que vous vous sentiez à l'aise tout au long de l'entrevue. Si, toutefois, vous vous sentiez mal à l'aise à n'importe quel moment au cours de l'entrevue, vous serez entièrement libre de vous arrêter quand vous le désirez. Si vous décidez de partager avec la chercheuse des informations personnelles qui concernent des comportements dangereux ou illégaux (au cas, par exemple, où votre enfant a été victime d'abus sexuels ou de harcèlement), la chercheuse sera dans l'obligation légale de faire part de ces informations aux autorités pertinentes (Société d'aide à l'enfance ou services de police, par exemple). Si vous partagez avec la chercheuse des informations qui pourraient exiger des ressources supplémentaires, la chercheuse vous fournira des renseignements sur les ressources disponibles ou les agences communautaires qui peuvent vous apporter un soutien dans ces situations.

### **CONFIDENTIALITÉ**

À moins que la loi ne l'exige, toutes les informations qui seront recueillies au cours de cette étude demeureront strictement confidentielles et elles seront conservées en lieu sûr aux bureaux du Programme d'autisme de l'Est de l'Ontario. Les informations recueillies dans cette étude seront conservées aux bureaux du Programme d'autisme de l'Est de l'Ontario pendant une période de 7 ans suivant la fin de l'étude; après cette période, toutes les informations brutes, transcriptions et notes de terrain seront déchiquetées et tous les enregistrements seront effacés. Toutes les transcriptions et notes de terrain et tous les fichiers audio seront protégés par un mot de passe et conservés sur une clé USB chiffrée. Tous les ordinateurs sur lesquels des informations seront conservées seront protégés par un mot de passe. Seule la chercheuse citée précédemment aura accès à ces informations. Pour que vos réponses demeurent anonymes, un code unique sera donné à toutes les informations qui auront été recueillies à votre sujet. Votre code n'aura aucun rapport avec les renseignements qui permettraient de connaître votre identité (tels que date de naissance ou autre).

### **PARTICIPATION**

Votre participation à cette étude est absolument volontaire. Vous n'êtes aucunement obligé(e) de participer. Vous avez également le droit de refuser de répondre à n'importe quelle question et *vous avez le droit de vous retirer de l'étude à n'importe quel moment sans aucune conséquence.*

### **RÉSULTATS**

Les résultats de cette étude seront publiés dans la thèse de doctorat de la chercheuse. De plus, ces résultats seront résumés dans un rapport qui sera remis aux personnes qui s'intéressent aux constatations de l'étude, y compris aux parents et aux jeunes qui auront participé à cette étude et aux agences qui travaillent en partenariat avec le Programme d'autisme de l'Est de l'Ontario. Il est possible également que les résultats de cette étude soient présentés à des conférences ou publiés dans des revues scientifiques à comité de lecture. Si les informations recueillies dans cette étude sont utilisées dans des publications ou pour des présentations professionnelles, elles demeureront totalement confidentielles et seront présentées dans leur ensemble.

### **POUR TOUT RENSEIGNEMENT SUPPLÉMENTAIRE**

Si vous désirez de plus amples renseignements concernant cette étude, n'hésitez pas à contacter la chercheuse :

**Nathalie Gougeon - candidate au doctorat, MS Ed, BCBA**

*Tél. : numéro de téléphone, adresse électronique*

Cette étude a reçu l'approbation du Comité d'éthique de la recherche du CHEO. Le Comité regroupe des scientifiques et des non-scientifiques dont la mission est d'évaluer les projets de recherche qui leur sont soumis. Ils ont la responsabilité d'assurer la protection des droits et du bien-être des personnes qui participent à des études de recherche. Pour tout renseignement concernant les droits des participants à une étude de recherche, vous pouvez contacter le président du Comité d'éthique de la recherche du CHEO, au *numéro de téléphone*. Veuillez noter, toutefois, que cette personne ne peut fournir aucun renseignement de santé concernant cette étude.



---

## FORMULAIRE DE CONSENTEMENT À UNE ENTREVUE POUR LES PARENTS/RESPONSABLES

**Titre de l'étude :** Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

**Chercheure :** Nathalie A. Gougeon, candidate au doctorat, MS Ed., BCBA

- J'ai lu les renseignements qui précèdent ou on m'en a informé(e), et je comprends ces renseignements. On m'a donné la possibilité de poser des questions et on a répondu à mes questions de façon satisfaisante.*
- On m'a remis une copie de ce formulaire de consentement dûment rempli et signé.*
- J'aimerais recevoir un résumé des résultats à la fin de l'étude.*

Je soussigné(e) \_\_\_\_\_ (votre nom en lettres moulées) accepte de participer à une **entrevue** dans le cadre de cette étude. Je comprends que mon entrevue sera enregistrée et que la chercheure aura le droit de citer mes déclarations. Si la chercheure me cite, il omettra toute information qui permettrait de connaître mon identité.

N° de téléphone : \_\_\_\_\_

Adresse postale : \_\_\_\_\_  
\_\_\_\_\_

Adresse courriel (facultatif) : \_\_\_\_\_

\_\_\_\_\_  
Nom du participant

\_\_\_\_\_  
Signature du participant

\_\_\_\_\_  
Date de la signature

\_\_\_\_\_  
Nom de la chercheure

\_\_\_\_\_  
Signature de la chercheure

\_\_\_\_\_  
Date de la signature

## **Guide d'entrevue pour les entrevues avec les parents/responsables**

Code de recherche : \_\_\_\_\_

- Remercier le participant d'avoir accepté de prendre part à une entrevue.
- Revoir brièvement, avec le participant, le formulaire de consentement – y compris le déroulement et la durée de l'entrevue – obtenir une copie du formulaire de consentement et en remettre une copie au participant.
- Obtenir la permission d'enregistrer l'entrevue.

### **Thèmes et questions possibles :**

(Note : ces questions visent à s'assurer que la chercheuse aura couvert tous les thèmes pertinents au cours de l'entrevue. Au fur et à mesure que le participant soulève divers thèmes, la chercheuse devrait l'inviter à donner de plus amples détails à ce sujet, en lui demandant d'apporter des précisions, de donner des exemples, etc.)

Merci d'avoir accepté de venir me parler, aujourd'hui, de la question de l'éducation à la sexualité de votre enfant. J'effectue donc une recherche sur l'éducation à la sexualité dans le cas des jeunes qui présentent l'autisme de haut niveau/le syndrome d'Asperger. Les constatations de cette étude seront notamment résumées dans un rapport où je présenterai les principaux résultats et des recommandations. À la fin de l'étude, les participants pourront obtenir une copie de ce rapport.

Avec votre permission, j'aimerais que vous me parliez - en tant que parent d'un jeune qui présente l'autisme de haut niveau/le syndrome d'Asperger - de votre point de vue et de votre expérience en ce qui concerne l'éducation à la sexualité pour ces jeunes adolescents.

Note : La chercheuse devrait expliquer clairement que, chaque fois que l'on parlera d'autisme dans le contexte de cette étude, il s'agira d'autisme de haut niveau/du syndrome d'Asperger.

### **PARTIE I :**

- 1. Ma première question, c'est : Quand on parle d' "éducation à la sexualité", qu'est-ce que cela veut dire pour vous? Dans le cas de votre enfant, qu'est-ce que l'éducation à la sexualité devrait couvrir, à votre avis?**

Questions de suivi :

1.a. Quels sont les principaux sujets ou les notions essentielles qui devraient être abordés, pour répondre aux besoins de votre enfant?

1.b. Est-ce qu'il y a d'autres sujets qui devraient être abordés pour répondre adéquatement aux besoins de votre enfant?

- 2. Est-ce qu'il y a des sujets qui ne devraient pas être abordés dans l' "éducation à la sexualité" de votre enfant?**

(Le cas échéant) Questions de suivi :

2.a. Est-ce qu'il y a d'autres sujets qui ne devraient pas être inclus dans l'éducation sexualité de votre enfant?

### **3. À votre avis, comment est-ce qu'on devrait enseigner l'éducation à la sexualité?**

Questions de suivi :

3.a. Quelle méthode d'enseignement correspondrait le mieux aux forces de votre enfant? À ses besoins?

3.b. Est-ce que vous pensez que ce serait mieux que l'éducation à la sexualité se fasse en groupe ou individuellement? Est-ce que l'éducation à la sexualité devrait se faire en groupes séparés, réservés exclusivement aux garçons / ou réservés exclusivement aux filles (citer groupe correspondant au sexe de l'enfant) ou bien est-ce que filles et garçons devraient être ensemble pour les cours d'éducation à la sexualité? Est-ce que vous pensez que votre enfant comprendrait mieux la sexualité si on la lui expliquait avec des supports visuels, ou dans une discussion interactive, ou par une présentation...? Est-ce qu'il y a d'autres façons qui permettraient à votre enfant de mieux comprendre la sexualité? Est-ce qu'il y a des méthodes qui pourraient bien fonctionner à votre avis?

### **4. À votre avis, qui est-ce qui devrait être responsable de l'éducation à la sexualité de votre enfant? Pourquoi?**

Questions de suivi :

4.a. Est-ce que vous considérez que la ou les personnes que vous avez citées sont bien préparées pour fournir une éducation à la sexualité à votre enfant? Pourquoi ou pourquoi pas?

4.b. Est-ce qu'il y a d'autres personnes qui pourraient s'occuper de l'éducation à la sexualité de votre enfant? Pourquoi?

4.c. (Le cas échéant) Est-ce que vous considérez que la ou les personnes que vous avez citées sont bien préparées pour fournir une éducation à la sexualité à votre enfant? Pourquoi ou pourquoi pas?

## **PARTIE II :**

### **5. Est-ce que votre enfant a suivi des cours d'éducation à la sexualité?**

Questions de suivi :

5.a. Qui lui a fourni cette éducation à la sexualité?

5.b. Est-ce que cette éducation à la sexualité a répondu aux besoins de votre enfant?

5.c. Pourquoi ou pourquoi pas?

### **6. Est-ce qu'il y a des problèmes ou des obstacles qui font que votre enfant ne peut pas - ou qu'il lui est très difficile de - recevoir une éducation à la sexualité adéquate?**

(Le cas échéant) Questions de suivi :

6.a. D'où viennent ces problèmes, à votre avis?

6.b. Est-ce qu'il y a d'autres raisons qui font que votre enfant ne peut pas recevoir une éducation à la sexualité adéquate?

6.c. (Le cas échéant) D'où viennent ces problèmes, à votre avis?

**7. Quand est-ce que ces problèmes/obstacles se produisent?**

Question de suivi :

7.a. À votre avis, pourquoi est-ce que ces problèmes/obstacles se produisent à ce moment-ci?

**8. À votre avis, de quelle façon est-ce que ces problèmes/obstacles influencent l'éducation à la sexualité que votre enfant peut recevoir?**

Question de suivi :

8.a. Est-ce que vous trouvez que ces problèmes/obstacles ont d'autres conséquences sur l'éducation à la sexualité que votre enfant peut recevoir?

**9. À votre avis, quels sont les soutiens qui permettent d'assurer une éducation à la sexualité à votre enfant?**

Questions de suivi :

9.a. À votre avis, pourquoi est-ce que ces soutiens existent?

9.b. Est-ce qu'il y a d'autres soutiens qui vous viennent à l'esprit?

9.c. (Le cas échéant) À votre avis, pourquoi est-ce que ces soutiens existent?

**10. Quand est-ce que ces soutiens sont disponibles?**

Question de suivi :

10.a. À votre avis, pourquoi ces soutiens sont-ils disponibles à ce moment-ci?

**11. À votre avis, de quelle façon est-ce que ces soutiens influencent l'éducation à la sexualité que votre enfant peut recevoir?**

Question de suivi :

11.a. Est-ce que ces soutiens ont d'autres conséquences sur l'éducation à la sexualité que votre enfant peut recevoir?

**PARTIE III :**

**12. À quel âge pensez-vous que votre enfant deviendra un adulte?**

**13. Qu'envisagez-vous pour votre enfant à cet âge (lorsqu'il deviendra un adulte)?**

**PARTIE IV :**

**14. Est-ce que vous êtes au courant de programmes ou de ressources d'éducation à la sexualité qui s'adressent aux jeunes comme votre enfant? Quels programmes ou ressources est-ce que vous connaissez?**

**15. Est-ce que ces programmes/ressources ont aidé votre enfant à apprendre des choses au sujet de la sexualité? De quelle(s) manière(s)?**

**16. Est-ce que vous trouvez qu'il manquait certaines choses, dans ces programmes ou dans ces ressources? (Le cas échéant : Qu'est-ce qui manquait?)**

**PARTIE V :**

**17. Est-ce qu'il y a d'autres questions qu'il aurait été pertinent de vous poser dans cette entrevue?**

**18. Est-ce que vous avez des commentaires au sujet de cette étude (*exemple : forces, faiblesses, suggestions, mode préféré de diffusion des résultats...*)?**

Merci beaucoup d'avoir pris le temps de discuter de ces questions importantes avec moi aujourd'hui. Je vous suis très reconnaissante de l'aide que vous m'avez apportée dans ma recherche sur l'éducation à la sexualité pour les jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger.

## Appendix Q: Youth Consent Form and Interview Rubric (English)



### **YOUTH INTERVIEW CONSENT FORM**

**Title of Study:** Conceptualizations of Sexuality Education for Youth with an Autism Spectrum Disorder

**Main Researcher:** Nathalie A. Gougeon, PhD Candidate, MS Ed, BCBA

#### **INTRODUCTION**

This study is being done as part of a Doctorate of Philosophy in Education from the University of Ottawa. Please take some time read and carefully consider the information below before you give your consent to take part in this study. This information will describe the purpose and procedures, as well as the possible risks and benefits of the study. You are encouraged to ask any questions you may have about the study to the main researcher of this study. If you agree to participate in this study, you will receive a copy of this consent form to keep. This study will be conducted in both English and French and you will have the choice of which language you would prefer.

#### **PURPOSE:**

You are invited to participate in a study looking at the sexuality education needs and experiences of youth with high-functioning autism/Asperger syndrome and their families. Some of the questions being asked as part of this study are personal in nature. The interview will ask your opinion related to sexuality education, what topics should be covered as part of sexuality education, who should be responsible for providing it, and so forth.

#### **PROCEDURES**

You are being asked to take part in an interview about your experience as a youth with high-functioning autism or Asperger syndrome.

The interview will take about 30 minutes to complete. The interview will take place either in person at your home or at an office of the Autism Program of Eastern Ontario and will be audio taped. The purpose of audio taping is to make sure that we are able to transcribe all of your feedback with accuracy. No one other than the main researcher and/or thesis committee members will have access to these recordings/transcriptions. You will have the option to complete the interview in either English or French.

#### **POSSIBLE BENEFITS**

There are no benefits from participating in this study; if your family is currently on the waitlist for ABA services, participating in this study will **not** change your position on this waitlist. However, this study will give you the chance to express your opinion and to provide the main researcher with important information on how to improve the delivery of sexuality education to youth with autism and their families. We hope that your information will help to develop a sexuality education program in the future, as well as provide information that will eventually improve policies and programs for youth with autism.

#### **POSSIBLE RISKS**

Because of the sensitive nature of the subject matter, you may feel uncomfortable answering some of the questions. The researcher will try to reduce any potential risks by making sure that all information is kept confidential, whenever possible. Every effort will be made to make sure that you are comfortable throughout the entire interview. If you feel uncomfortable during the interview and wish to stop, you are free to do so at any time. If you choose to share personal information that involves illegal or dangerous behaviours (for example, if you were victim of sexual

abuse or bullying), the researcher will be required by law to share this information with proper authorities (for example, the Children's Aid Society or police services). If you share information that may require additional resources, the researcher will provide you with information on available resources and/or community agencies that can support this situation.

### **CONFIDENTIALITY**

Unless required by law, all information collected during the study will be kept entirely confidential and will be stored in a secure place at the offices of the Autism Program of Eastern Ontario. The study information will be stored at the Autism Program of Eastern Ontario for 7 years following the end of the study, after which time all the raw information we have collected will be destroyed. All information we collect will be password protected and stored on an encrypted USB stick. All computers used for this study will be password protected. Only the above-mentioned researchers will have access to the information. In order to keep your answers anonymous, a unique code will be assigned to all information collected about you. Your code will not be based on any identifying information (date of birth, for example).

### **PARTICIPATION**

Your participation in the study is entirely voluntary. You do not have to participate in this study. You can choose not to answer any of the questions and *you have the right to pull out of the study at any time, without consequence.*

### **RESULTS**

The results of this study will be published in the main researcher's doctoral thesis. Also, the results of this study will be put in a report which will be shared with the people who have an interest in the results, including parents and youth participating in this study, as well as partner agencies. There is also the possibility that research results will be presented at conferences or published in peer-reviewed journals. While the information may also be used in future publications and presentations, it will remain confidential and all survey information will be reported as combined information.

### **CONTACT INFORMATION**

If you have any questions or need more information about the study, please contact:

#### **Main Researcher, PhD Candidate, MS Ed, BCBA:**

*Nathalie Gougeon, phone number, e-mail address*

The CHEO Research Ethics Board (REB) has approved this study. The REB is a group of individuals from scientific and non-scientific backgrounds who review research study projects. Their goal is to ensure the protection of the rights and welfare of people involved in research. For information regarding patients' rights in research studies, you may contact the Chair of the Research Ethics Board at *phone number*, although this person cannot provide any health-related information about the study.



### YOUTH INTERVIEW CONSENT FORM

**Title of Study:** Conceptualizations of Sexuality Education for Youth an Autism Spectrum Disorder

**Principal Investigators:** Nathalie A. Gougeon, PhD Candidate, MS Ed. , BCBA

- I have read or been informed of and I understand the above information. I was able to ask questions and my questions have been fully answered.*
- I have been given a copy of this signed consent form.*
- I would like to receive a summary of the results at the end of the study.*

I \_\_\_\_\_ agree to participate in an **interview** for this study. I understand that my  
*(please print your name)*

interview will be audiotaped and I understand that I may be quoted. If I am quoted, all personally identifying information will be removed.

Telephone Number: \_\_\_\_\_

Mailing Address: \_\_\_\_\_  
\_\_\_\_\_

E-mail Address (optional): \_\_\_\_\_

\_\_\_\_\_  
Study participant's name

\_\_\_\_\_  
Study participant's signature

\_\_\_\_\_  
Date signed

*If the participant is under 16, or if the child is 16 or older but is not able to consent for him/herself, parent must also sign below:*

\_\_\_\_\_  
Parent's name

\_\_\_\_\_  
Parent's signature

\_\_\_\_\_  
Date signed

\_\_\_\_\_  
Investigator's name

\_\_\_\_\_  
Investigator's signature

\_\_\_\_\_  
Date signed

## Interview Guide for Youth

Research ID: \_\_\_\_\_

- Thank participant for agreeing to interview.
- Review consent form and interview process and duration, obtain one copy of consent form and give one copy to participant.
- Obtain permission for audio recording of interview.

### Themes and possible questions:

(note: these questions are meant to ensure that all themes are covered during the interview. The interviewer should elaborate on topics raised by the interviewee by asking follow-up questions, requesting an elaboration, etc.).

Thank you for agreeing to speak with us today regarding your sexuality education. We are conducting research on sexuality education for youth with high-functioning autism/Asperger syndrome. A result of this project will be a summary of the key findings and suggestions taken from the study. This will be shared with study participants and will be available at the end of this project.

With your permission, we would like to ask you about your views and experience as an individual with autism with regards to your sexuality education.

### PART I:

**1. My first question has to do with what ‘sexuality education’ means for you. In your opinion, what should ‘sexuality education’ include?**

Follow-up questions:

- 1.a. What are some of the topics that you think should be covered that would meet your needs?
- 1.b. Are there any other topics you feel are important to meet your needs?

**2. Are there any topics that you feel should not be part of ‘sexuality education’?**

Follow-up questions:

- 2.a. Are there any other topics you feel should not be part of ‘sexuality education’ for you?

**3. How do you think sexuality education should be presented?**

Follow-up questions:

- 3.a. What teaching approach would best serve your strengths? Your needs?
- 3.b. For sexuality education, do you think you would learn better in a group format or an individual learning format? Would you prefer to learn about sexuality with just other boys/girls (use same gender of interviewee) or in a mixed group with boys and girls together? Do you think you would learn better about sexuality through visual supports, through interactive discussion, through lecture or? Are there other ways

you feel you would learn better about sexuality? Are there any particular approaches that you think would be more useful for you?

**4. Who do you think should be responsible for providing/delivering sexuality education to you? Why?**

Follow-up questions:

4.a. Do you feel that 'state person' is well-prepared to provide you with/deliver sexuality education? Why or why not?

4.b. Is there anyone else you think should be responsible to provide you/deliver with sexuality education? Why?

4.c. Do you feel that 'state person' is well-prepared to provide you with/deliver sexuality education? Why or why not?

**PART II:**

**5. Have you taken part in sexuality education in the past?**

Follow-up questions:

5.a. Who delivered it/provided it to you?

5.b. Did it meet your needs? Did you benefit from it? Did you like it?

5.c. Why or why not?

**6. In your opinion, what are some of the things (problems) that stop you from/get in the way of receiving sexuality education?**

Follow-up questions:

6.a. Why do you think these problems exist?

6.b. Are there any other things that you can think of that might stop you from getting sexuality education?

6.c. Why do you think these problems exist?

**7. When do these problems show up?**

Follow-up question:

7.a. Why do you think they show up at this time?

**8. In what ways do you feel these problems affect the ways you get sexuality education?**

Follow-up question:

8.a. Are there other ways you feel these problems affect how you get sexuality education?

**9. In your view, what are the things (supports) that help you to get sexuality education?**

Follow-up questions:

9.a. Why do you think these supports help you to get sexuality education?

9.b. Are there any other supports you can think of?

9.c. Why do you think these supports help you to get sexuality education?

**10. When do these supports show up?**

Follow-up question:

10.a. Why do you think these supports show up at this time?

**11. In what ways do you feel these supports affect the ways you get sexuality education?**

Follow-up question:

11.a. Are there other ways you feel these supports affect how you get sexuality education?

### **PART III:**

**12. At what age will you consider yourself an adult?**

**13. What do you see for yourself at that age/when you are an adult?**

### **PART IV:**

**14. Do you know any sexuality education programs or resources for you? What are they?**

**15. Have they helped you to learn about sexuality? How/In what ways?**

**16. Was there anything missing from this/these program(s)/resource(s)? What was it?**

### **PART V:**

**17. Are there any other questions you think we should have asked you during this interview?**

**18. Do you have any comments you would like to share about this study (*e.g., strengths, weaknesses, suggestions, preferred format for dissemination of findings*)?**

Thank you for taking the time to speak with me today. I appreciate you assisting me with my research project on sexuality education for youth with autism.

## Appendix R: Youth Consent Form and Interview Rubric (French)



uOttawa

### **FORMULAIRE DE CONSENTEMENT À UNE ENTREVUE À L'INTENTION DES JEUNES PARTICIPANTS**

**Titre de l'étude :** Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

**Chercheur :** Nathalie A. Gougeon, candidate au doctorat, MS Ed, BCBA

#### **INTRODUCTION**

La chercheuse mène cette étude dans le cadre de son doctorat en Éducation (Université d'Ottawa). Prenez le temps de lire les renseignements qui suivent très attentivement avant de consentir à participer à l'étude. Les renseignements ci-dessous expliquent l'objectif de l'étude, son déroulement, ainsi que ses risques et avantages potentiels. Nous vous encourageons à obtenir tout renseignement supplémentaire auprès de la chercheuse. Si vous acceptez de participer à cette étude, nous vous remettons une copie de ce formulaire, que vous pourrez conserver. L'étude sera menée en français et en anglais : vous aurez donc le choix d'y participer dans l'une ou l'autre de ces langues.

#### **OBJECTIF DE L'ÉTUDE**

Vous êtes invité(e) à participer à une étude qui examinera les besoins et l'expérience des jeunes qui présentent l'autisme de haut niveau/le syndrome d'Asperger et de leurs familles dans le domaine de l'éducation à la sexualité. Certaines des questions qui seront posées dans le cadre de cette étude sont de nature personnelle. Dans l'entrevue, on vous demandera de donner votre opinion concernant l'éducation à la sexualité, concernant quels sujets devraient être abordés dans l'éducation à la sexualité, concernant qui devrait être responsable de l'éducation à la sexualité, etc.

#### **DÉROULEMENT DE L'ÉTUDE**

Nous vous invitons à participer à une entrevue où vous pourrez parler de votre expérience à titre de jeune qui présente l'autisme de haut niveau/le syndrome d'Asperger.

L'entrevue durera environ 30 minutes. Elle sera effectuée en personne, soit chez vous, soit à l'un des bureaux du Programme d'autisme de l'Est de l'Ontario. Toutes les entrevues seront enregistrées, afin d'aider la chercheuse à faire une transcription exacte et complète des déclarations des participants. Personne n'aura accès aux déclarations enregistrées/transcriptions en dehors de la chercheuse et des membres de son comité de thèse. Vous aurez le choix de faire l'entrevue en français ou en anglais.

#### **AVANTAGES POTENTIELS**

La participation à cette étude ne présente aucun avantage pour les participants; si votre famille est actuellement sur une liste d'attente pour recevoir des services d'ACA, votre participation à cette étude ne changera **pas** votre position sur cette liste. Toutefois, cette étude vous donnera la possibilité d'exprimer votre point de vue et de fournir à la chercheuse des informations importantes concernant les moyens d'améliorer la prestation de l'éducation à la sexualité auprès des jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger et de leurs familles. Notre espoir est que les informations que vous nous fournirez nous permettront d'élaborer un curriculum pertinent et, par la suite, d'améliorer les politiques et les programmes pour les jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger.

### **RISQUES POTENTIELS**

Étant donné la nature délicate du sujet, il est possible que vous vous sentiez mal à l'aise de répondre à certaines des questions. La chercheuse s'efforcera de réduire ce risque potentiel en s'assurant, dans la mesure du possible, que vos informations demeureront confidentielles. La chercheuse fera également tout son possible pour que vous vous sentiez à l'aise tout au long de l'entrevue. Si, toutefois, vous vous sentiez mal à l'aise à n'importe quel moment au cours de l'entrevue, vous serez entièrement libre de vous arrêter quand vous le désirez. Si vous décidez de partager avec la chercheuse des informations personnelles qui concernent des comportements dangereux ou illégaux (au cas, par exemple, où vous avez été victime d'abus sexuels ou de bullying/harcèlement sexuel), la chercheuse sera dans l'obligation légale de faire part de ces informations aux autorités pertinentes (Société d'aide à l'enfance ou services de police, par exemple). Si vous partagez avec la chercheuse des informations qui pourraient exiger des ressources supplémentaires, la chercheuse vous fournira des renseignements sur les ressources disponibles ou les agences communautaires qui pourraient vous apporter un soutien dans ces situations.

### **CONFIDENTIALITÉ**

À moins que la loi ne l'exige, toutes les informations qui seront recueillies au cours de cette étude demeureront strictement confidentielles et elles seront conservées en lieu sûr aux bureaux du Programme d'autisme de l'Est de l'Ontario. Les informations recueillies dans cette étude seront conservées aux bureaux du Programme d'autisme de l'Est de l'Ontario pendant une période de 7 ans suivant la fin de l'étude; après cette période, toutes les informations brutes, transcriptions et notes de terrain seront déchiquetées et tous les enregistrements seront effacés. Toutes les transcriptions et notes de terrain et tous les fichiers audio seront protégés par un mot de passe et conservés sur une clé USB chiffrée. Tous les ordinateurs sur lesquels des informations seront conservées seront protégés par un mot de passe. Seule la chercheuse citée précédemment aura accès à ces informations. Pour que vos réponses demeurent anonymes, un code unique sera donné à toutes les informations qui auront été recueillies à votre sujet. Votre code n'aura aucun rapport avec les renseignements qui permettraient de connaître votre identité (tels que date de naissance ou autre).

### **PARTICIPATION**

Votre participation à cette étude est absolument volontaire. Vous n'êtes aucunement obligé(e) de participer. Vous avez également le droit de refuser de répondre à n'importe quelle question et *vous avez le droit de vous retirer de l'étude à n'importe quel moment sans aucune conséquence.*

### **RÉSULTATS**

Les résultats de cette étude seront publiés dans la thèse de doctorat de la chercheuse. De plus, ces résultats seront résumés dans un rapport qui sera remis aux personnes qui s'intéressent aux constatations de l'étude, y compris aux parents et aux jeunes qui auront participé à cette étude et aux agences qui travaillent en partenariat avec le Programme d'autisme de l'Est de l'Ontario. Il est possible également que les résultats de cette étude soient présentés à des conférences ou publiés dans des revues scientifiques à comité de lecture. Si les informations recueillies dans cette étude sont utilisées dans des publications ou pour des présentations professionnelles, elles demeureront totalement confidentielles et seront présentées dans leur ensemble.

### **POUR TOUT RENSEIGNEMENT SUPPLÉMENTAIRE**

Si vous désirez de plus amples renseignements concernant cette étude, n'hésitez pas à contacter la chercheuse :

**Nathalie Gougeon - candidate au doctorat, MS Ed, BCBA :**

*Tél. : numéro de téléphone, adresse électronique*

Cette étude a reçu l'approbation du Comité d'éthique de la recherche du CHEO. Le Comité regroupe des scientifiques et des non-scientifiques dont la mission est d'évaluer les projets de recherche qui leur sont soumis. Ils ont la responsabilité d'assurer la protection des droits et du bien-être des personnes qui participent à des études de recherche. Pour tout renseignement concernant les droits des participants à une étude de recherche, vous pouvez contacter le président du Comité d'éthique de la recherche du CHEO, au *numéro de téléphone*. Veuillez noter, toutefois, que cette personne ne peut fournir aucun renseignement de santé concernant cette étude.



## FORMULAIRE DE CONSENTEMENT À UNE ENTREVUE POUR LES JEUNES PARTICIPANTS

**Titre de l'étude :** Conceptualisations de l'éducation à la sexualité pour les jeunes présentant un trouble du spectre autistique

**Chercheure :** Nathalie A. Gougeon, candidate au doctorat, MS Ed., BCBA

- J'ai lu les renseignements qui précèdent ou on m'en a informé(e), et je comprends ces renseignements. On m'a donné la possibilité de poser des questions et on a répondu à mes questions de façon satisfaisante.*
- On m'a remis une copie de ce formulaire de consentement dûment rempli et signé.*
- J'aimerais recevoir un résumé des résultats à la fin de l'étude.*

Je soussigné(e) \_\_\_\_\_ (votre nom en lettres moulées) accepte de participer à une **entrevue** dans le cadre de cette étude. Je comprends que mon entrevue sera enregistrée et que la chercheure aura le droit de citer mes déclarations. Si la chercheure me cite, elle omettra toute information qui permettrait de connaître mon identité.

N° de téléphone : \_\_\_\_\_

Adresse postale : \_\_\_\_\_  
\_\_\_\_\_

Adresse courriel (facultatif) : \_\_\_\_\_

\_\_\_\_\_  
Nom du participant à l'étude

\_\_\_\_\_  
Signature du participant à l'étude

\_\_\_\_\_  
Date de signature

*Si le jeune participant a moins de 16 ans, ou que le jeune participant a entre 16 et 18 ans mais n'est pas en mesure de donner son consentement, un parent doit également signer ci-dessous.*

\_\_\_\_\_  
Nom du parent

\_\_\_\_\_  
Signature du parent

\_\_\_\_\_  
Date de signature

\_\_\_\_\_  
Nom de la chercheure

\_\_\_\_\_  
Signature de la chercheure

\_\_\_\_\_  
Date de signature

## **Guide d'entrevue pour les entrevues avec les jeunes participants**

Code de recherche : \_\_\_\_\_

- Remercier le participant d'avoir accepté de prendre part à une entrevue.
- Revoir brièvement, avec le participant, le formulaire de consentement – y compris le déroulement et la durée de l'entrevue – obtenir une copie du formulaire de consentement et en remettre une copie au participant.
- Obtenir la permission d'enregistrer l'entrevue.

### **Thèmes et questions possibles :**

(Note : ces questions visent à s'assurer que la chercheuse aura couvert tous les thèmes pertinents au cours de l'entrevue. Au fur et à mesure que le participant soulève divers thèmes, la chercheuse devrait l'inviter à donner de plus amples détails à ce sujet, en lui demandant d'apporter des précisions, de donner des exemples, etc.)

Merci d'avoir accepté de venir me parler, aujourd'hui, de la question de l'éducation à la sexualité. J'effectue donc une recherche sur l'éducation à la sexualité dans le cas des jeunes qui présentent l'autisme de haut niveau/le syndrome d'Asperger. Les constatations de cette étude seront notamment résumées dans un rapport où je présenterai les principaux résultats et des recommandations. À la fin de l'étude, les participants pourront obtenir une copie de ce rapport.

Avec ta permission, j'aimerais que tu me donnes ton point de vue et que tu me parles de ton expérience - en tant que jeune présentant l'autisme de haut niveau/le syndrome d'Asperger - concernant l'éducation à la sexualité.

### **PARTIE I :**

- 1. Ma première question, c'est : Quand on parle d' "éducation à la sexualité", qu'est-ce que cela veut dire pour toi? À ton avis, qu'est-ce que l'éducation à la sexualité devrait couvrir?**

Questions de suivi :

1.a. Quels sont les principaux sujets ou les notions essentielles qui devraient être abordés, pour répondre à tes besoins?

1.b. Est-ce qu'il y a d'autres sujets qui devraient être abordés pour répondre adéquatement à tes besoins?

- 2. Est-ce qu'il y a des sujets qui ne devraient pas être abordés dans l' "éducation à la sexualité"?**

(Le cas échéant) Questions de suivi :

2.a. Est-ce qu'il y a d'autres sujets qui ne devraient pas être inclus dans ton éducation à la sexualité?

### **3. À ton avis, comment est-ce qu'on devrait enseigner l'éducation à la sexualité?**

Questions de suivi :

3.a. Quelle méthode d'enseignement correspondrait le mieux à tes forces? À tes besoins?

3.b. Est-ce que tu penses que ce serait mieux que l'éducation à la sexualité se fasse en groupe ou individuellement? Est-ce que tu préférerais que l'éducation à la sexualité se fasse en groupes séparés, réservés exclusivement aux garçons / ou réservés exclusivement aux filles (citer groupe correspondant au sexe du jeune participant) ou bien est-ce que filles et garçons devraient être ensemble pour les cours d'éducation à la sexualité? Est-ce que tu penses que tu comprendrais mieux la sexualité si on te l'expliquait avec des supports visuels, ou dans une discussion interactive, ou par une présentation...? Est-ce qu'il y a d'autres façons qui te permettraient de mieux comprendre la sexualité? Est-ce qu'il y a des méthodes qui pourraient bien fonctionner à ton avis?

### **4. À ton avis, qui est-ce qui devrait être responsable de ton éducation à la sexualité? Pourquoi?**

Questions de suivi :

4.a. Est-ce que tu trouves que cette ou ces personnes sont bien préparées pour te fournir une éducation à la sexualité? Pourquoi ou pourquoi pas?

4.b. Est-ce qu'il y a d'autres personnes qui pourraient s'occuper de ton éducation à la sexualité? Pourquoi?

4.c. (Le cas échéant) Est-ce que tu trouves que cette ou ces personnes-là sont bien préparées pour te fournir une éducation à la sexualité? Pourquoi ou pourquoi pas?

## **PARTIE II :**

### **5. Est-ce que tu as reçu des cours d'éducation à la sexualité?**

Questions de suivi :

5.a. Qui t'a fourni cette éducation à la sexualité?

5.b. Est-ce que cette éducation à la sexualité a répondu à tes besoins? Est-ce que ça t'a été utile? Est-ce que tu es content(e) d'avoir eu ces cours?

5.c. Pourquoi ou pourquoi pas?

**6. Est-ce qu'il y a des problèmes ou des obstacles qui font que tu ne peux pas - ou qu'il t'est très difficile de - recevoir une éducation à la sexualité adéquate?**

(Le cas échéant) Questions de suivi :

6.a. D'où viennent ces problèmes, à ton avis?

6.b. Est-ce qu'il y a d'autres raisons qui font que tu ne peux pas recevoir une éducation à la sexualité adéquate?

6.c. (Le cas échéant) D'où viennent ces problèmes, à ton avis?

**7. Quand est-ce que ces problèmes/obstacles se produisent?**

Question de suivi :

7.a. À ton avis, pourquoi est-ce que ces problèmes/obstacles se produisent à ce moment-ci?

**8. À ton avis, de quelle façon est-ce que ces problèmes/obstacles influencent l'éducation à la sexualité que tu peux recevoir?**

Question de suivi :

8.a. Est-ce que tu trouves que ces problèmes/obstacles ont d'autres conséquences sur l'éducation à la sexualité que tu peux recevoir?

**9. À ton avis, quelles sont les choses (les soutiens) qui te permettent d'avoir accès à une éducation à la sexualité?**

Questions de suivi :

9.a. En quoi est-ce que ces soutiens t'aident à recevoir une éducation à la sexualité?

9.b. Est-ce qu'il y a d'autres soutiens qui te viennent à l'esprit?

9.c. (Le cas échéant) À ton avis, pourquoi est-ce que ces soutiens t'aident à recevoir une éducation à la sexualité?

**10. Quand est-ce que ces soutiens sont disponibles?**

Question de suivi :

10.a. À ton avis, pourquoi est-ce que ces soutiens sont disponibles à ce moment-ci?

**11. À ton avis, de quelle façon est-ce que ces soutiens influencent l'éducation à la sexualité que tu peux recevoir?**

Question de suivi :

11.a. Est-ce que ces soutiens ont d'autres conséquences sur l'éducation à la sexualité que tu peux recevoir?

**PARTIE III :**

**12. À quel âge penses-tu que tu seras un adulte?**

**13. Qu'envisages-tu pour ta vie à cet âge (lorsque tu seras un adulte)?**

**PARTIE IV :**

**14. Est-ce que tu es au courant de programmes ou de ressources d'éducation à la sexualité qui s'adressent aux jeunes comme toi? Quels programmes ou ressources est-ce que tu connais?**

**15. Est-ce que ces programmes/ressources t'ont aidé(e) à apprendre des choses au sujet de la sexualité? De quelle(s) manière(s)?**

**16. Est-ce que tu trouves qu'il manquait certaines choses, dans ces programmes ou dans ces ressources? (Le cas échéant : Qu'est-ce qui manquait?)**

**PARTIE V :**

**1. Est-ce qu'il y a d'autres questions que tu trouves que j'aurais dû te poser dans cette entrevue?**

**2. Est-ce que tu as des commentaires au sujet de cette étude (exemple : forces, faiblesses, suggestions, mode préféré de diffusion des résultats...)?**

Merci beaucoup d'avoir pris le temps de discuter de ces questions importantes avec moi aujourd'hui. Je te suis très reconnaissante de l'aide que tu m'as apportée dans ma recherche sur l'éducation à la sexualité pour les jeunes présentant l'autisme de haut niveau/le syndrome d'Asperger.

## Appendix S: Resource List (English)

### Sexuality Resources for Individuals with an Autism Spectrum Disorder and their Parents:

Please note that this list is not exhaustive. It provides a list of websites, organizations, resources, and relevant professionals. Visiting or contacting the websites, organizations or professionals will provide many links to other sites and resources that can specifically meet your needs.

#### General information on sexuality/sexuality education:

ASHA (American Social Health Association) website: [www.ashastd.org](http://www.ashastd.org)

This website provides information on sensitive sexuality topics, especially regarding Sexually Transmitted Infections (STIs). It is a US-based site and therefore geared to needs of Americans, however, it does have relevant and accurate information on STIs, including information for teens. There is also a section for parents on how to talk to your teen about sexual health. There are resources you can order (for a fee).

The Canadian Federation for Sexual Health website: [www.cfsh.ca](http://www.cfsh.ca)

The Canadian Federation for Sexual Health is a pro-choice, charitable organization dedicated to promoting sexual and reproductive health and rights in Canada and internationally. It provides information on various topics related to sexuality, and contains sections dedicated to parents and youth.

CATIE website: [www.catie.ca](http://www.catie.ca)

This website is dedicated to providing information on HIV and Hepatitis C to Canadians.

NICHCY (National Dissemination Center for Children with Disabilities) Connections to Sexuality Education website: [www.nichcy.org/resources/sexualityeducation.asp](http://www.nichcy.org/resources/sexualityeducation.asp)

This is a US-based website that contains a list of web resources relating to sexuality education and disabilities, including useful links for youth and parents. Some of these are out of date, but many are still relevant and practical.

Sexual Health Network website: [www.sexualhealth.com](http://www.sexualhealth.com)

This US-based site provides easy access to all topics related to sexuality, including sexual topics about disability. Provides information, education, support, and resources.

Sexuality and U website: [www.sexualityandu.ca](http://www.sexualityandu.ca)

Sexuality and U is a Canadian web site committed to providing accurate, credible and up-to-date information and education on sexual health. An initiative of the Society of Obstetricians and Gynaecologists of Canada, the site's mandate is to provide guidance and advice to help individuals develop and maintain a healthy sexuality. There are dedicated sections for parents and for youth.

SIECCAN (Sex Information and Education Council of Canada) website: [www.sieccan.org](http://www.sieccan.org)

SIECCAN is a non-profit Canadian organization that promotes sexuality education and provides information to the public and to professionals about topics related to sexuality.

SIECUS (Sex Information and Education Council of the United States) website: [www.siecus.org](http://www.siecus.org)  
SIECUS is the US equivalent of SIECCAN. It also provides a wealth of information on all topics relating to sexuality. This site contains a link to sexuality organizations worldwide. It also contains links to sexuality education publications which includes lesson plans.

Susan's Sex Support Site website: [www.sexsupport.org](http://www.sexsupport.org):

This is a website that has been created by a self-advocate. It is for people who have a disability who would like information on sexuality education, personal advocacy, personal empowerment, and personal support regarding their sexuality. It is geared for adolescents and older. It has many links that may be of help for the individual or advocate seeking for information or help on sexuality issues.

**For information on topics, issues, concerns related to sexual orientation/sexual identity:**

**Organizations and websites:**

Sexuality and U website: [www.sexualityandu.ca](http://www.sexualityandu.ca)

This website contains a section dedicated to sexual identity and orientation.

The Canadian Federation of Sexual Health website: [www.cfsh.ca](http://www.cfsh.ca)

This website contains a section dedicated to sexual identity and orientation, including a section for GLBT individuals living with a disability.

Kids Help Phone website: [www.kidshelpphone.ca](http://www.kidshelpphone.ca)

Kids Help Phone is Canada's only toll-free, 24-hour, bilingual anonymous and confidential [phone counselling](#), [web counselling](#) and referral service for children and youth. Professional counsellors provide support to young people across the country. This organization provides counselling on topics such as abuse, bullying, friends, dating, sexual orientation, etc. To contact Kids Help Phone, call: *phone number*.

PFLAG Ottawa website: [www.gaycanada.com/pflag-ottawa](http://www.gaycanada.com/pflag-ottawa)

This organization provides support for parents, families, friends, and spouses of lesbian, gay, bisexual and transgender people in the Ottawa area. PFLAG Ottawa can be contacted at the following number: *phone number*.

**Organizations and professionals:**

If you (if you are a youth with autism) or if you are the parent of a child who has been sexually abused, and you are not sure what next steps to take, below are some organizations that can help:

The Children's Aid Society of Ottawa website: [www.casott.on.ca](http://www.casott.on.ca)

The Children's Aid Society (CAS) is a non-profit community organization mandated to protect children and youth from abuse and neglect. If you live in the Ottawa area, you can report abuse by contacting CAS Ottawa at: *phone number*.

The Children's Aid Society of the United Counties of Stormont, Dundas & Glengarry website: [www.cassdg.ca](http://www.cassdg.ca)

The Children's Aid Society (CAS) is a non-profit community organization mandated to protect children and youth from abuse and neglect. If you live in the Stormont, Dundas & Glengarry (SD&G) area, you can report abuse by contacting CAS of SD&G at: *phone number*.

Family & Children's Services of the County of Renfrew website: [www.fcsrenfrew.on.ca](http://www.fcsrenfrew.on.ca)  
Family & Children's Services of the County of Renfrew provides equivalent services to the Children's Aid Society in the region of Renfrew County. If you live in the Renfrew County area, you can report abuse by contacting Family & Children's Services of the County of Renfrew toll free at: *phone number*.

Valoris website: [www.integra-pr.ca](http://www.integra-pr.ca)  
Valoris provides equivalent services to the Children's Aid Society in the region of Prescott-Russell. If you live in the Prescott-Russell area, you can report abuse by contacting Valoris at: *phone number*.

Distress Centre – Ottawa and Region website: [www.dcottawa.on.ca](http://www.dcottawa.on.ca)  
The Distress Centre provides counselling and support to people in the Ottawa region who are lonely, depressed, or distressed. The centre is available 24 hours a day and is confidential. To contact the Distress Centre of Ottawa and Region, call: *phone number*.

Kids Help Phone website: [www.kidshelpphone.ca](http://www.kidshelpphone.ca)  
Kids Help Phone is Canada's only toll-free, 24-hour, bilingual anonymous and confidential [phone counselling](#), [web counselling](#) and referral service for children and youth. Professional counsellors provide support to young people across the country. This organization provides counselling on topics such as abuse, bullying, friends, dating, sexual orientation, etc. To contact Kids Help Phone, call: *phone number*.

### **Other organizations that support individuals with an Autism Spectrum Disorder and their families:**

Autism Ontario website: [www.autismontario.com](http://www.autismontario.com)  
Autism Ontario is a non-profit organization which aims to ensure that each individual with autism is provided the means to achieve quality of life as a respected member of society. It is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families, and the professionals with whom they interact. The association and its chapters share common goals of providing information and education, supporting research, and advocating for programs and services for the autism community.

La société franco-ontarienne de l'autisme website : [www.autismefranco.ca](http://www.autismefranco.ca)

La société franco-ontarienne de l'autisme aims to address the needs of Franco-Ontarian individuals with autism and their families through advocacy.

Y's Owl Maclure Co-Operative Centre website: [www.ysowlmaclure.ca](http://www.ysowlmaclure.ca)

This is a non-profit organization for individuals with disabilities living in Ottawa. It offers various courses, including sexuality education to adolescents with an Autism Spectrum Disorder. Note: There is a fee for the courses offered.

### **If you are looking for a Psychological Professional in your Area:**

The College of Psychologists of Ontario website: [www.cpo.on.ca](http://www.cpo.on.ca)

The College of Psychologists of Ontario is the regulatory body for the profession of psychology in the Province of Ontario. You can use this site to search for a practicing psychologist in your area. You can also search according to area of practice, authorized client population, as well as language of service.

Ottawa Academy of Psychology website: [www.ottawa-psychologists.org](http://www.ottawa-psychologists.org)

This is an online directory of Psychologists and Psychological Associates in the Ottawa area who are members of the Ottawa Academy of Psychology.

For Psychologists with specialization in sexuality issues for individuals with Autism Spectrum Disorders (including Asperger's Syndrome):

Dr. Isabelle Hénault's website: [www.psychologue-montreal.ca/psychologue/isabelle-henault.php](http://www.psychologue-montreal.ca/psychologue/isabelle-henault.php)

Dr. Isabelle Hénault, is a psychologist located in Montréal (Québec). Her practice and studies have focused on providing diagnosis, education and support to children, adolescents, adults and couples living with Asperger's Syndrome. Dr. Hénault has developed a relationships and sex education program, and works with individuals and groups to increase their understanding of sexuality, and conducts relationship counseling. She also offers workshops on autism and Asperger's Syndrome

### **Curricula & Other Resources:**

#### **Books for Parents:**

[Asperger's Syndrome and Sexuality: From Adolescence through Adulthood](#). Dr. Isabelle Hénault. (Jessica Kingsley Publisher, London, 2006). This book provides social-sexual information for sexuality issues/education for individuals with Asperger's Syndrome. Includes reproducible handouts for sexuality education lessons.

[Autism & Sexuality: A Guide for Instruction](#). Susan Gray, Lisa Ruble, and Nancy Dalrymple. (Autism Society of Indiana, 1996). A 25 page booklet on autism and sexuality, and how to address common issues.

[Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know about Pre-Teen and Teenage Years](#). Dr. Shana Nichols. (Jessica Kingsley Publishers, London, 2009).

This book covers areas specific to girls on the autism spectrum, including friendship and social status, menstruation, gynaecological examinations, sexuality, etc.

Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges. Catherine Davies, Melissa Dubie. (AAPC Publishing, Shawnee Mission Kansas, 2012). This book contains a comprehensive curriculum to teach various aspects of sexuality, including social, safety, and sensory aspects related to the needs of individuals with Asperger Syndrome. Includes a CD with reproducible handouts and activities.

I Openers: Parents Ask Questions About Sexuality and Children with Developmental Disabilities. Dave Hingsburger. (Family Support Institute Press, Vancouver, 1993). Provides answers to common questions.

Taking Care of Myself: A Hygiene, Puberty, & Personal Curriculum for Young People with Autism. Mary Wrobel. (Future Horizons, 2003). A book with reproducible stories for social understanding and other interventions covering daily living skills, puberty, body changes, and appropriate/inappropriate touch.

### **Resources to support the teaching of appropriate and safe masturbation:**

#### **For Women:**

Finger Tips: Teaching Women with Disabilities About Masturbation Through Understanding and Video. Dave Hingsburger and Sandra Haar. (Diverse City Press, 2000). This is a graphic, respectful and accurate instructional video for female masturbation.

#### **For Men:**

Hand Made Love: A Guide to Teaching about Male Masturbation. Dave Hingsburger. (Diverse City Press, 1995). This is a graphic, respectful and accurate instructional video for male masturbation.

### **Resource supporting teaching privacy seeking behaviour (for masturbation and other behaviours) for women and men:**

Taking Care of Myself: A Hygiene, Puberty, & Personal Curriculum for Young People with Autism. Mary Wrobel. (Future Horizons, 2003). A book with reproducible stories for social understanding and other interventions covering daily living skills, privacy seeking behaviour, appropriate/inappropriate touch.

### **Books for Children & Adolescents:**

Autism-Asperger's and Sexuality: Puberty and Beyond. Jerry and Mary Newport. (Future Horizons, 2002). Written for adolescents and young adults with an Autism Spectrum Disorder by a husband and wife who are also on the autism spectrum. Higher-level reading abilities required.

Freaks, Geeks & Asperger Syndrome. Luke Jackson. (Jessica Kingsley Publishers, London, 2002). Written by a 13 year old boy with Asperger's Syndrome, this book offers information on friendships, social situations, bullying, dating, etc.

**Websites that sell sexuality education curricula:**

Program Development Associates' website: [www.disabilitytraining.com/ddse.html](http://www.disabilitytraining.com/ddse.html)

This is a website that offers various curricula for teaching individuals with disabilities, including an entire section on sex education. These curricula are for purchase through the website.

Parent Books Store website: [www.parentbooks.ca](http://www.parentbooks.ca)

This Canadian website offers many of the resources found in this list.

The James Stanfield Company website: [www.stanfield.com/sexed.html](http://www.stanfield.com/sexed.html)

This website offers a variety of curricula for the teaching of social and sexuality educational skills, including the classic "Circles" curriculum. This curriculum provides a starting point for teaching individuals the ins and outs of relationships with all people, levels of intimacy, and appropriate and inappropriate social behaviours. It provides visual representations of relationships and the difference between self/others, public/private.

## Appendix T: Resource List (French)

### Ressources sur la sexualité à l'intention des personnes présentant un trouble du spectre autistique et de leurs parents

Veillez noter que cette liste n'est pas exhaustive. Ce document fournit une liste de sites Web, d'organismes, de ressources et de professionnels pertinents. En consultant ces sites Web ou ces professionnels, vous découvrirez un grand nombre d'autres sites et d'autres ressources qui pourront répondre à vos besoins précis.

#### Informations générales concernant la sexualité/l'éducation sexuelle

Site Web de l'*ASHA (American Social Health Association)* : [www.ashastd.org](http://www.ashastd.org) (site en anglais exclusivement). Ce site Web fournit des informations sur des sujets délicats reliés à la sexualité, en particulier sur les infections sexuellement transmissibles. C'est un site américain, qui s'adresse donc tout spécialement aux Américains, cependant, ce site fournit des informations exactes et pertinentes sur les infections sexuellement transmissibles, qui s'adressent notamment aux adolescents. Ce site contient aussi une section pour les parents, où l'on suggère diverses façons de parler à un adolescent de questions de santé sexuelle. On peut également commander certaines ressources (payantes) par l'intermédiaire de ce site.

Site Web de la *Fédération canadienne pour la santé sexuelle* : <http://www.cfsh.ca/fr/Default.aspx> (version française)

La *Fédération canadienne pour la santé sexuelle* est un organisme de bienfaisance pro-choix qui se consacre à l'avancement de la santé et des droits sexuels et génésiques au Canada et à l'étranger. Sur ce site, vous trouverez des informations sur divers sujets reliés à la sexualité, y compris des sections à l'intention des parents et des adolescents.  
(version anglaise : *The Canadian Federation for Sexual Health* [www.cfsh.ca](http://www.cfsh.ca))

Site Web de *CATIE* : <http://www.catie.ca/fr/accueil> (version française)  
Source canadienne de renseignements sur le VIH et l'hépatite C.  
(version anglaise de *CATIE* : [www.catie.ca](http://www.catie.ca))

Site Web de *NICHCY (National Dissemination Center for Children with Disabilities)* Lien vers les ressources sur la sexualité/l'éducation sexuelle :

[www.nichcy.org/resources/sexualityeducation.asp](http://www.nichcy.org/resources/sexualityeducation.asp) (site en anglais exclusivement)

Ce site américain contient une liste de ressources internet reliées à l'éducation sexuelle pour les personnes handicapées, y compris des liens utiles pour les parents et les adolescents. Certains des liens ne sont pas à jour, mais beaucoup sont toujours pertinents et ils proposent des solutions pratiques.

Site Web du *Sexual Health Network* : [www.sexualhealth.com](http://www.sexualhealth.com) (site en anglais exclusivement)  
Site américain où il est facile de trouver des informations sur tous les sujets reliés à la sexualité, y compris dans le contexte de divers troubles/handicaps. Ce site fournit informations, éducation, soutiens et ressources.

Site Web de *MaSexualite.ca* : <http://www.masexualite.ca/> (version française)  
Site canadien qui s'est donné pour mandat de fournir une éducation et des informations exactes et à jour concernant la santé sexuelle. Ce site a été créé à l'initiative de la Société des obstétriciens et gynécologues du Canada. Son objectif est d'informer et de conseiller les intéressés, pour qu'ils puissent avoir une sexualité saine. Le site comporte des sections spécialement destinées aux parents et aux adolescents.  
(version anglaise de *MaSexualite.ca* : *Sexuality and U* [www.sexualityandu.ca](http://www.sexualityandu.ca))

Site Web du *SIECCAN* (*Sex Information and Education Council of Canada*) : [www.sieccan.org](http://www.sieccan.org)  
(site en anglais exclusivement)  
Le *SIECCAN* est un organisme de bienfaisance canadien qui s'efforce de promouvoir l'éducation sexuelle et qui fournit des informations au public et aux professionnels concernant les sujets reliés à la sexualité.

Site Web de *SIECUS* (*Sex Information and Education Council of the United States*) : [www.siecus.org](http://www.siecus.org) (site en anglais exclusivement)  
Le *SIECUS* est l'équivalent américain du *SIECCAN* (mentionné précédemment). Ce site fournit une foule d'informations sur tous les sujets qui se rapportent à la sexualité. On y trouve aussi des liens vers des organismes du monde entier qui se spécialisent dans l'éducation sexuelle. De plus, ce site offre des liens vers des publications qui incluent des plans de cours dans le domaine de l'éducation sexuelle.

Site Web de *Susan's Sex Support Site* : [www.sexsupport.org](http://www.sexsupport.org) (site en anglais exclusivement)  
Ce site a été créé par un défenseur des droits des personnes handicapées. Il s'adresse aux personnes avec des troubles/handicaps qui veulent s'informer au sujet de l'éducation sexuelle, de la défense des droits individuels, du pouvoir de décision individuel, et du soutien personnel dans la sexualité. Le site s'adresse aux adolescents et aux adultes. Il offre une richesse de liens qui pourraient être utiles à une personne qui cherche à se renseigner ou qui recherche de l'aide au sujet de la sexualité.

## **Informations sur les sujets et questions reliés à l'orientation sexuelle/l'identité sexuelle**

### **Organismes et sites Web**

Site Web de *MaSexualite.ca* : <http://www.masexualite.ca/> (version française)  
Ce site contient une section réservée à l'identité et à l'orientation sexuelles.  
(version anglaise de *MaSexualite.ca* : *Sexuality and U* [www.sexualityandu.ca](http://www.sexualityandu.ca))

Site Web de la *Fédération canadienne pour la santé sexuelle* : <http://www.cfsh.ca/fr/Default.aspx> (version française)  
Ce site contient une section réservée à l'identité et à l'orientation sexuelles, y compris une section destinée aux personnes GLBT (lesbiennes, gays, bisexuels et transgenres) atteints de troubles/handicaps.

(version anglaise : *The Canadian Federation for Sexual Health* [www.cfsh.ca](http://www.cfsh.ca))

*Jeunessejecoute.ca* : <http://jeunessejecoute.ca/Teens/Home.aspx?lang=fr-ca> (version française)  
*Jeunesse J'écoute* est le seul service au Canada où, 24 heures sur 24, les enfants et les adolescents peuvent téléphoner (gratuitement) pour obtenir des conseils (strictement confidentiels) en français ou en anglais. *Jeunesse J'écoute*, c'est aussi un site Web où les jeunes peuvent obtenir des conseils par voie électronique. *Jeunesse J'écoute* offre notamment des services d'orientation pour les jeunes. Des conseillers professionnels apportent le soutien dont ils ont besoin aux jeunes de tout le Canada. Cet organisme offre du counseling dans le domaine des abus, du bullying, des relations intimes, de l'orientation sexuelle, etc. Pour contacter un conseiller de *Jeunesse J'écoute*, téléphonez au *numéro de téléphone*.

(version anglaise : *Kids Help Phone* [www.kidshelpphone.ca](http://www.kidshelpphone.ca) Tél. : *numéro de téléphone*)

Site Web de *PFLAG Ottawa* : [www.gaycanada.com/pflag-ottawa](http://www.gaycanada.com/pflag-ottawa) (site en anglais exclusivement)  
*PFLAG Ottawa* est un organisme d'entraide qui s'adresse aux parents, familles, conjoints et amis de lesbiennes, gays, bisexuels et transgenres qui habitent la région d'Ottawa. Vous pouvez contacter cet organisme au *numéro de téléphone*.

## Organismes et professionnels

Si vous êtes un jeune autiste qui a été victime d'abus sexuels, ou que vous êtes le parent d'un enfant qui a été victime d'abus sexuels, et que vous ne savez pas quoi faire, vous trouverez ci-dessous une liste d'organismes qui pourront vous aider :

Site Web de la *Société de l'aide à l'enfance d'Ottawa* : <http://www.casott.on.ca/fr/> (version française)

La *Société de l'aide à l'enfance* est un organisme communautaire à but non lucratif qui a pour mandat de protéger les enfants et adolescents contre les abus et la négligence. Si vous habitez dans la région d'Ottawa, vous pouvez signaler des abus à la *Société de l'aide à l'enfance d'Ottawa* en composant le *numéro de téléphone*.

(version anglaise : *The Children's Aid Society of Ottawa* [www.casott.on.ca](http://www.casott.on.ca) *numéro de téléphone*)

Site Web de la *Société de l'aide à l'enfance des comtés unis de Stormont, Dundas & Glengarry* : <http://www.cassdg.ca/index.php?lang=fr>

La *Société de l'aide à l'enfance* est un organisme communautaire à but non lucratif qui a pour mandat de protéger les enfants et adolescents contre les abus et la négligence. Si vous habitez dans les comtés de Stormont, Dundas ou Glengarry, vous pouvez signaler des abus à la *Société de l'aide à l'enfance des comtés unis de Stormont, Dundas & Glengarry* en composant le *numéro de téléphone*.

(version anglaise : *The Children's Aid Society of the United Counties of Stormont, Dundas & Glengarry* [www.cassdg.ca](http://www.cassdg.ca) *numéro de téléphone*)

Site Web de l'organisme *Family & Children's Services of the County of Renfrew* : [www.fcsrenfrew.on.ca](http://www.fcsrenfrew.on.ca) (site en anglais exclusivement)

L'organisme *Family & Children's Services of the County of Renfrew* fournit, dans le comté de Renfrew, des services équivalents à ceux que fournit la *Société de l'aide à l'enfance*. Si vous habitez dans le comté de Renfrew, vous pouvez signaler des abus à l'organisme *Family & Children's Services of the County of Renfrew* en composant le *numéro de téléphone* (sans frais).

Site Web de l'organisme *Valoris* : [www.integra-pr.ca](http://www.integra-pr.ca) (en français et en anglais)  
L'organisme *Valoris* fournit, dans la région de Prescott-Russell, des services équivalents à ceux que fournit la *Société de l'aide à l'enfance*. Si vous habitez dans la région de Prescott-Russell, vous pouvez signaler des abus en contactant *Valoris* au *numéro de téléphone*.

Site Web du *Centre de détresse de la région d'Ottawa/Ottawa and Region Distress Centre* : [www.dcottawa.on.ca](http://www.dcottawa.on.ca) (site presque exclusivement en anglais)

Le *Centre de détresse/Distress Centre* fournit du counseling et un soutien aux personnes de la région d'Ottawa qui se sentent seules, déprimées ou en détresse. Ces services sont offerts 24 heures sur 24, et ils sont strictement confidentiels. Pour contacter le *Centre de détresse d'Ottawa*, composez le *numéro de téléphone*.

*Jeunessejecoute.ca* : <http://jeunessejecoute.ca/Teens/Home.aspx?lang=fr-ca> (version française)  
*Jeunesse J'écoute* est le seul service au Canada où, 24 heures sur 24, les enfants et adolescents peuvent téléphoner (gratuitement) pour obtenir des conseils (strictement confidentiels) en français ou en anglais. *Jeunesse J'écoute*, c'est aussi un site Web où les jeunes peuvent obtenir des conseils par voie électronique. *Jeunesse J'écoute* offre notamment des services d'orientation pour les jeunes. Des conseillers professionnels apportent le soutien dont ils ont besoin aux jeunes de tout le Canada. Cet organisme offre du counseling dans le domaine des abus, du bullying, des relations intimes, de l'orientation sexuelle, etc. Pour contacter un conseiller de *Jeunesse J'écoute*, téléphonez au *numéro de téléphone*.  
(version anglaise : *Kids Help Phone* [www.kidshelpphone.ca](http://www.kidshelpphone.ca) Tél. : *numéro de téléphone*)

## **Autres organismes de soutien qui s'adressent aux personnes autistes et à leurs familles**

Site Web de *Autism Ontario* : [www.autismontario.com](http://www.autismontario.com) (site essentiellement en anglais, avec une section française progressivement de plus en plus vaste)

*Autism Ontario* est un organisme à but non lucratif qui s'efforce de faire en sorte que toutes les personnes autistes parviennent à une qualité de vie et deviennent des membres respectés de la société. Son mandat est de sensibiliser le public aux réalités de l'autisme et aux difficultés quotidiennes auxquelles font face les personnes autistes, leurs familles et les professionnels avec qui elles sont en contact. Cet organisme et ses sections locales poursuivent les objectifs communs de fournir des informations et une éducation, de soutenir la recherche, et de promouvoir les programmes et services destinés à la communauté autiste.

Site Web de la *Société franco-ontarienne de l'autisme* : [www.autismefranco.ca](http://www.autismefranco.ca) (site en français exclusivement)

La *Société franco-ontarienne de l'autisme* s'efforce de répondre aux besoins des autistes franco-ontariens et de leurs familles en défendant leurs intérêts.

Site Web de *Y's Owl Maclure Co-Operative Centre* : [www.ysowlmaclure.ca](http://www.ysowlmaclure.ca) (site en anglais exclusivement)

Organisme à but non lucratif destiné aux personnes handicapées de la région d'Ottawa. Cet organisme offre divers cours, y compris des cours d'éducation sexuelle à l'intention des adolescents autistes. Note : Les cours sont payants.

## **Si vous recherchez un psychologue professionnel dans votre région**

Site Web de l'*Ordre des psychologues de l'Ontario/College of Psychologists of Ontario* [www.cpo.on.ca](http://www.cpo.on.ca) (site en anglais exclusivement)

L'*Ordre des psychologues de l'Ontario* est l'organisme responsable de la réglementation des psychologues professionnels en Ontario. Sur ce site, vous pourrez rechercher le nom d'un psychologue professionnel qui exerce dans la région où vous habitez. Vous pourrez également y faire une recherche par domaine de spécialisation, clients autorisés, et langue de services (termes de recherche en anglais : *area of practice, authorized client population, language of service*).

Site Web de l'*Académie de psychologie d'Ottawa/Ottawa Academy of Psychology* : [www.ottawa-psychologists.org](http://www.ottawa-psychologists.org) (site en français et en anglais)

Répertoire en ligne de psychologues et d'associés en psychologie agréés de la région d'Ottawa qui sont membres de l'*Académie de psychologie d'Ottawa*.

## **Psychologue spécialisé dans les questions de sexualité associées aux troubles du spectre autistique (y compris au syndrome d'Asperger)**

Site Web du Dr Isabelle Hénault : [www.psychologue-montreal.ca/psychologue/isabelle-henault.php](http://www.psychologue-montreal.ca/psychologue/isabelle-henault.php) (site presque exclusivement en français)

Le Dr Isabelle Hénault est psychologue à Montréal (Québec). Son travail et sa recherche se concentrent essentiellement sur le diagnostic, l'éducation et le soutien des enfants, adolescents, adultes et couples présentant le syndrome d'Asperger. Le Dr Hénault a mis au point un programme éducatif sur les relations et l'éducation sexuelles; elle assure des consultations individuelles et en groupe pour développer la compréhension de la sexualité, et elle organise également des séances de counseling sur les relations affectives/sexuelles. Elle donne aussi des ateliers sur l'autisme et le syndrome d'Asperger.

## **Matériel pédagogique & autres ressources**

### **Livres pour les parents**

Le syndrome d'Asperger et la sexualité. Dr. Isabelle Hénault. (Éditions Chenelière-Éducation, Montréal, 2006). Ce livre fournit des informations au sujet des questions de sexualité/d'éducation sexuelle qui concernent les personnes présentant le syndrome d'Asperger. Inclut des sections que l'on peut reproduire pour des cours d'éducation sexuelle.

(version anglaise : [Asperger's Syndrome and Sexuality: From Adolescence through Adulthood](#). Dr. Isabelle Hénault. Jessica Kingsley Publisher, London, 2006).

[Autism & Sexuality: A Guide for Instruction](#). Susan Gray, Lisa Ruble, and Nancy Dalrymple. (Autism Society of Indiana, 1996). Livret de 25 pages sur la sexualité dans le cas des personnes autistes, avec des suggestions pour répondre aux problèmes courants.

[Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know about Pre-Teen and Teenage Years](#). Dr. Shana Nichols. (Jessica Kingsley Publishers, London, 2009). Ce livre porte sur les questions qui concernent les jeunes filles autistes, y compris l'amitié et le statut social, les menstruations, les examens gynécologiques et la sexualité.

[Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges](#). Catherine Davies, Melissa Dubie. (AAPC Publishing, Shawnee Mission Kansas, 2012). Ce livre contient un curriculum très complet pour enseigner divers aspects de la sexualité, y compris les questions sociales, les questions de sécurité, et les aspects sensoriels associés aux besoins des personnes présentant le syndrome d'Asperger. Inclut un CD qui contient des sections et des activités que l'on peut reproduire.

[I Openers: Parents Ask Questions About Sexuality and Children with Developmental Disabilities](#). Dave Hingsburger. (Family Support Institute Press, Vancouver, 1993). Apporte des réponses aux questions qu'on se pose souvent.

[Taking Care of Myself: A Hygiene, Puberty, & Personal Curriculum for Young People with Autism](#). Mary Wrobel. (Future Horizons, 2003). Livre d'histoires sociales (que l'on peut reproduire) qui peut servir à enseigner la compréhension sociale ou dans d'autres interventions portant sur les habiletés de la vie quotidienne, la puberté, les changements physiques, les façons appropriées & inappropriées de toucher autrui, etc.

## **Ressources pour accompagner l'enseignement de pratiques de masturbation appropriées et sans danger**

### **Pour les jeunes femmes**

[Finger Tips: Teaching Women with Disabilities About Masturbation Through Understanding and Video](#). Dave Hingsburger and Sandra Haar. (Diverse City Press, 2000). Vidéo éducative explicite qui présente les techniques de masturbation féminine avec respect et exactitude.

### **Pour les jeunes hommes**

[Hand Made Love: A Guide to Teaching about Male Masturbation](#). Dave Hingsburger. (Diverse City Press, 1995). Vidéo éducative explicite qui présente les techniques de masturbation masculine avec respect et exactitude.

## **Ressource (pour jeunes hommes et femmes) pour encourager à rechercher l'intimité quand la situation l'exige (pour masturbation et autres comportements exigeant une intimité)**

Taking Care of Myself: A Hygiene, Puberty, & Personal Curriculum for Young People with Autism. Mary Wrobel. (Future Horizons, 2003). Livre d'histoires sociales (que l'on peut reproduire) qui peut servir à enseigner la compréhension sociale ou dans d'autres interventions portant sur les habiletés de la vie quotidienne, la recherche de l'intimité quand la situation l'exige, les façons appropriées & inappropriées de toucher autrui, etc.

## **Livres pour enfants et adolescents**

Autism-Asperger's and Sexuality: Puberty and Beyond. Jerry and Mary Newport. (Future Horizons, 2002). Ouvrage rédigé par un couple autiste (l'auteur et sa femme sont tous deux autistes) et qui s'adresse aux adolescents et jeunes adultes autistes. Note : Cet ouvrage exige des aptitudes de lecture d'un niveau supérieur.

Freaks, Geeks & Asperger Syndrome. Luke Jackson. (Jessica Kingsley Publishers, London, 2002). Rédigé par un jeune garçon de 13 ans avec le syndrome d'Asperger, ce livre fournit des informations concernant les relations amicales, les situations sociales, le bullying, les relations sentimentales, etc.

## **Sites Web de vente de matériel pédagogique pour l'éducation sexuelle**

Site Web de *Program Development Associates* : [www.disabilitytraining.com/ddse.html](http://www.disabilitytraining.com/ddse.html)  
Ce site Web offre diverses ressources à l'intention des apprenants qui présentent des troubles/handicaps, y compris toute une section de matériel pédagogique sur l'éducation sexuelle. Ces ressources pédagogiques sont en vente sur le site.

Site Web de *Parent Books Store* : [www.parentbooks.ca](http://www.parentbooks.ca)  
Ce site canadien offre un grand nombre des ressources qui ont été citées dans cette liste.

Site Web de la *James Stanfield Company* : [www.stanfield.com/sexed.html](http://www.stanfield.com/sexed.html)  
Ce site offre une grande variété de matériel pédagogique pour l'enseignement des habiletés sociales et l'éducation sexuelle, y compris le curriculum anglais classique intitulé "Circles". Ce curriculum constitue un bon point de départ pour enseigner les divers mécanismes des relations avec diverses personnes, les divers degrés d'intimité, et les comportements sociaux appropriés et inappropriés. Offre notamment des représentations visuelles des relations et des différences entre soi/autrui et public/privé.

## Appendix U: Summary of Dimensions of Sexuality Education Modality

(According to Youth, Caregivers, and as Supported by Extant Texts)

*Table U1*

Summary of Dimensions of Sexuality Education Modality According to Youth, Caregivers and as Supported by Extant Texts

Modality	Youth	Caregivers	Literature	Policy	Curricula
Responsibility					
R1: Caregivers	7/9	11/11	Ballan, 2012, Chan & John, 2012; Kalyva, 2010; Koller, 2000; Meister et al., 1994; Mitchell, 2010; Nichols & Blakeley-Smith, 2009; Nichols et al., 2009; Roth, 2009; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Travers & Tincani, 2010; Wolfe et al., 2009	McKay & Bissell, 2010; Murphy & Roy Elias, 2006; PHAC, 2008; SIECUS, 2004	Davies & Dubie, 2012; Hénault, 2006; MEDU, 1999; MEDU, 2000; MEDU, 2010a; 2010b
R2: School	8/9	11/11	Ballan, 2012; Chan & John, 2012; Kalyva, 2010; Koller, 2000; Mitchell, 2010; Nichols & Blakeley-Smith, 2009; Nichols et al., 2009; Roth, 2009; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Travers & Tincani, 2010; Wolfe et al., 2009	McKay & Bissell, 2010; Murphy & Roy Elias, 2006; PHAC, 2008; SIECUS, 2004	Davies & Dubie, 2012; Hénault, 2006; MEDU, 1999; MEDU, 2000; MEDU, 2010a; 2010b
R3: Community partners/professionals	1/9	11/11	Ballan, 2012; Chan & John, 2012; Kalyva, 2010; Koller, 2000; Mitchell, 2010; Nichols & Blakeley-Smith, 2009; Nichols et al., 2009; Roth, 2009; Sullivan & Caterino, 2008; Tarnai & Wolfe,	McKay & Bissell, 2010; Murphy & Roy Elias, 2006; PHAC, 2008; SIECUS, 2004	Davies & Dubie, 2012; Hénault, 2006; MEDU, 1999; MEDU, 2000; MEDU, 2010a; 2010b

Modality	Youth	Caregivers	Literature	Policy	Curricula
			2008; Travers & Tincani, 2010; Wolfe et al., 2009		
R4: Peers	1/9 (though some identified peers as supports)	0/11 (though some identified peers as supports)	Nichols et al., 2009; Wolfe et al., 2009	PHAC, 2008	MEDU, 1999; MEDU, 2000
R5: Self/Youth	--	--	Hingsburger & Tough (2002)	SIECUS, 2004	MEDU, 2010a; 2010b
Educator Attributes					
EA1: Personal traits	8/9	10/11	--	--	Davies & Dubie, 2012 (creativity; sense of humour)
EA2: Relevant experience/knowledge	7/9	0/11	Ballan, 2012; Hatton & Tector, 2010; Kalyva, 2010; Meister et al., 1994; Nichols & Blakeley-Smith, 2009; Nichols et al., 2009; Sullivan & Caterino, 2008; Travers & Tincani, 2010	McKay & Bissell, 2010; PHAC, 2008; SIECUS, 2004	Davies & Dubie, 2012 Personal experience (Davies & Dubie, 2012)
EA3: Knowledge of autism profile	--	10/11	Ballan, 2012; Hatton & Tector, 2010; Nichols & Blakeley-Smith, 2009; Nichols et al., 2009; Sullivan & Caterino, 2008	--	Davies & Dubie, 2012
EA4: Alignment of goals with family values	0/9	5/11	Ballan, 2012; Chan & John, 2012; Hatton & Tector, 2010; Tissot, 2009; Wolfe et al., 2009	McKay & Bissell, 2010; PHAC, 2008; SIECUS, 2004	--

Modality	Youth	Caregivers	Literature	Policy (individual, family, and greater community values)	Curricula
EA5: Sexual rights training/perspective	--	--	Hingsburger & Tough, 2002; Meister et al, 1994; Sullivan & Caterino, 2008	Murphy & Roy Elias, 2006;	--
Provision					
P1: Group only	6/9	0/11	--	--	Davies & Dubie, 2012; Hénault, 2006 (group ideal)
P2: Mix of 1:1 and group	3/9	10/11	Nichols et al., 2009 (dependent on individual); Tissot, 2009	--	MEDU, 2010a; 2010b
P3: Individualized	0/9	0/11	Ballan, 2012; Chan & John, 2012; Hatton & Tector, 2010; Hellemans et al., 2007; Koller, 2000; Mitchell, 2010; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Wolfe et al., 2009	PHAC, 2008	--
P3: Congregated by gender (partly or fully)	0/9	10/11	Nichols et al., 2009; Roth, 2009 (fully)	--	MEDU, 2010a; 2010b (partly)
P4: Mixed gender	6/9	0/11	--	--	Davies & Dubie, 2012; Hénault, 2006

<b>Modality</b>	<b>Youth</b>	<b>Caregivers</b>	<b>Literature</b>	<b>Policy</b>	<b>Curricula</b>
P5: Congregated by disorder (partly or fully)	--	10/11	Hatton & Tector, 2010; Nichols & Blakeley-Smith, 2009; Roth, 2009; Tissot, 2009	--	Davies & Dubie, 2012 (fully); Hénault, 2006 (fully)

*Note.* While every attempt has been made to ensure that this table is as comprehensive as possible, it is not exhaustive.

## Appendix V: Summary of Sexuality Education Content

(According to Youth, Caregivers and as Supported by Extant Texts)

*Table VI*

Summary of Sexuality Education Content According to Youth, Caregivers and as Supported by Extant Texts

<b>Content</b>	<b>Youth</b>	<b>Caregivers</b>	<b>Literature</b>	<b>Policy</b>	<b>Curricula</b>
C1: Facts	6/9	11/11	Ballan, 2012; Blanchett & Wolfe, 2002; Chan & John, 2012; Gerhardt, 2006; Hatton & Tector, 2010; Hingsburger & Tough, 2002; Koegel & LaZebnik, 2009; Koller, 2000; Meister et al., 1994; Mitchell, 2010; Nichols & Blakeley-Smith, 2009; Nichols et al., 2009; Ray et al., 2004; Roth, 2009; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Tissot, 2009; Travers & Tincani, 2010; Wolfe et al., 2009	McKay & Bissell, 2010; Murphy & Roy Elias, 2006; PHAC, 2008; SIECUS, 2004	Davies & Dubie, 2012; Hénault, 2006; MEDU, 1999; MEDU, 2000; MEDU, 2010a; 2010b
C2: Contextualized socio-sexual behaviours/norms	7/9 (rules & timelines)	11/11	Ballan, 2012; Blanchett & Wolfe, 2002; Chan & John, 2012; Gerhardt, 2006; Hatton & Tector, 2010; Hellemans et al., 2007; Hingsburger & Tough, 2002; Kalyva, 2010; Koegel & LaZebnik, 2009; Koller, 2000; Mehzabin & Stokes, 2011; Meister et al., 1994; Mitchell, 2010; Nichols & Blakeley-Smith, 2009; Nichols et al., 2009; Roth,	McKay & Bissell, 2010; Murphy & Roy Elias, 2006; PHAC, 2008; SIECUS, 2004	Davies & Dubie, 2012; Hénault, 2006; MEDU, 1999; MEDU, 2000; MEDU, 2010a; 2010b

Content	Youth	Caregivers	Literature	Policy	Curricula
			2009; Stokes & Kaur, 2005; Stokes et al., 2007; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Tissot, 2009; Travers & Tincani, 2010; Wolfe et al., 2009		
C3: Safety	4/9	11/11	Ballan, 2012; Blanchett & Wolfe, 2002; Chan & John, 2012; Gerhardt, 2006; Hatton & Tector, 2010; Hellemans et al., 2007; Hingsburger & Tough, 2002; Kalyva, 2010; Koegel & LaZebnik, 2009; Koller, 2000; Meister et al., 1994; Mitchell, 2010; Nichols & Blakeley-Smith, 2009; Nichols et al., 2009; Roth, 2009; Stokes & Kaur, 2005; Stokes et al., 2007; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Tissot, 2009; Travers & Tincani, 2010; Wolfe et al., 2009	McKay & Bissell, 2010; Murphy & Roy Elias, 2006; PHAC, 2008; SIECUS, 2004	Davies & Dubie, 2012; Hénault, 2006; MEDU, 1999; MEDU, 2000; MEDU, 2010a; 2010b
C4: Normalization of sexual behaviour	--	10/11	Ballan, 2012; Blanchett & Wolfe, 2002; Chan & John, 2012; Hatton & Tector, 2010; Hellemans et al., 2007; Hingsburger & Tough, 2002; Meister et al., 1994; Mitchell, 2010; Nichols et al., 2009; Roth, 2009; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Travers & Tincani, 2010; Wolfe et al., 2009	McKay & Bissell, 2010; Murphy & Roy Elias, 2006; PHAC, 2008 (adopts 'optimal sexual health' instead of 'normalization'); SIECUS, 2004	Davies & Dubie, 2012; Hénault, 2006; MEDU, 2010a

<b>Content</b>	<b>Youth</b>	<b>Caregivers</b>	<b>Literature</b>	<b>Policy</b>	<b>Curricula</b>
C5 : Enjoyment	2/9	2/9 (implicit in some normalization discussions)	Hingsburger & Tough, 2002; Nichols et al., 2009; Roth, 2009; Tarnai & Wolfe, 2008	Murphy & Roy Elias, 2006; PHAC, 2008; SIECUS, 2004	Davies & Dubie, 2012; Hénault, 2006; MEDU, 2010a
C6: Delayed timing of content to balance developmental and physical maturity	--	7/11	Gerhardt, 2006; Hatton & Tector, 2010; Lawson, 2005; Nichols et al., 2009; Stokes & Kaur, 2005; Sullivan & Caterino, 2008; Wolfe et al., 2009	PHAC, 2008; SIECUS, 2004	MEDU, 2010a; 2010b
C7: Proactive delivery (starting at young age)	--	--	Ballan, 2012; Gerhardt, 2006; Koegel & LaZebnik, 2009; Mehzabin & Stokes, 2011; Mitchell, 2010; Moxon, in Middletown Centre for Autism, n.d.;	Murphy & Roy Elias, 2006	--

*Note.* While every attempt has been made to ensure that this table is as comprehensive as possible, it is not exhaustive.

## Appendix W: Summary of Manifestations of Sexuality Education

(According to Youth, Caregivers, and as Supported by Extant Texts)

*Table W1*

Summary of Manifestations of Sexuality Education According to Youth, Caregivers and as Supported by Extant Texts

Manifestation	Youth	Caregivers	Literature	Policy	Curricula
D1: Formal only (discrete)	--	0/11	Hatton & Tector, 2010; Kalyva, 2010; Koller, 2000; Tissot, 2009	--	Davies & Dubie, 2012; Hénault, 2006
D2: Informal only	--	0/11	--	--	--
D3: Overarching (formal and informal)	--	11/11	Koegel & LaZebnik, 2009; Mitchell, 2010; Nichols et al., 2009; Tarnai & Wolfe, 2008	PHAC, 2008	MEDU, 1999; MEDU, 2000; MEDU, 2010a; 2010b

## **Appendix X: Complete and Interim Sexuality Contents of the Revised Ontario Curriculum, Grades 1 to 8: Health and Physical Education**

**(MEDU, 1998/2005; 2010a; 2010b)<sup>20</sup>**

### **Health Topics (Interim Edition)**

Growth and development education is more than simply teaching young people about the anatomy and physiology of reproduction. For example, growth and development education focuses on an understanding of sexuality in its broadest context – sexual development, reproductive health, interpersonal relationships, affection, abstinence, body image, and gender roles. Acquiring information and skills and developing attitudes, beliefs, and values related to identity and relationships are lifelong processes. Parents and guardians are the primary educators of their children. As children grow and develop relationships with family members and others, they learn about appropriate behaviours and values, as well as about sexuality. They are influenced by parents, friends, relatives, religious leaders, teachers, and neighbours, as well as by television, radio, videos, movies, books, advertisements, music, and newspapers. School-based programs add another important dimension to a child’s ongoing learning about sexuality. The overall and specific expectations in this strand are age-appropriate and should be addressed with sensitivity and respect for individual differences. Because of the sensitive nature of these topics, parents or guardians must be informed about the content of the curriculum and time of delivery. Teachers and learners must develop a comfort level with these topics so that information can be discussed openly, honestly, and in an atmosphere of mutual respect. The “healthy sexuality” expectations should be addressed only after teachers have developed rapport with their students. Opportunities should be provided for segregated as well as coeducational instruction (MEDU, 2010b, p.33).

### **Healthy Living Strand - Grades 1 to 3 (Interim Edition)**

In the primary grades, students are introduced to basic health concepts, given opportunities to apply this knowledge to decisions about their own health, and encouraged to make connections between their health and well-being and their interactions with others and the world around them. Particular emphasis is placed on having students learn how to take responsibility for their own safety, at home and in the community, how to stand up for themselves, and how to get help in situations of abuse. Students also learn to understand and apply basic concepts related to healthy food choices, healthy relationships, diversity, and substance use and potentially addictive behaviours. They learn the names of body parts, begin to understand how their bodies work and develop, and acquire an understanding of some of the factors that contribute to healthy physical and emotional development (MEDU, 2010b, p. 69).

### **Healthy Living Strand - Grades 4 to 6 (Interim Edition)**

In the junior grades, students continue to develop an understanding of the factors that contribute to their health and the health of others in their family and community, but

---

<sup>20</sup> Items from the unedited version of this document which have been excluded from the interim edition have been boxed for easier identification. The unedited version of the curriculum was obtained through People for Education (2013).

with a particular focus on choices and decisions connected to their personal health. Their ability to make healthy eating decisions is further developed as they acquire additional knowledge about nutrition and nutritional labelling, and as they learn how to understand and manage their food choices and set healthy eating goals for themselves.

As they become more independent and more responsible for their own safety and that of others, they also learn how to assess risk, respond to dangerous situations, and protect themselves from a variety of social dangers, including bullying, abuse, violence, and technology-related risks. They learn about the hazards of tobacco, alcohol, illicit drugs, and addictive behaviours and develop the decision-making and communication skills needed to resist pressures to engage in risky behaviour.

Because students at this age are approaching or beginning puberty, the curriculum expectations provide an opportunity for students to develop the knowledge and skills that they will need to understand the physical, emotional, and social changes that they are experiencing or are about to go through. Topics include reproduction, self-concept, relationships, stress management, and decision making.

Students who are well informed, who have had the opportunity to do some thinking in advance, and who have been able to practise the appropriate decision-making skills are likely to make wiser decisions about their health (MEDU, 2010b, 115)

### **Healthy Living Strand - Grades 7-8 (Interim Edition)**

Students will continue to learn about the factors that contribute to healthy development and consider how that information connects to their personal health choices and to the health of others in the world around them. In the intermediate grades, they will focus on making connections between their own health and the health and well-being of those around them.

Grade 7 and 8 students add to their knowledge of healthy eating practices by acquiring a deeper understanding of nutritional concepts and the relationship between nutrition and disease, as well as learning more advanced approaches to managing their own food intake, making healthy food choices, and promoting healthy eating to others.

The study of personal safety and injury prevention expands to include situations that students in these grades may encounter as they become more independent and active in a wider variety of situations and environments, including online and virtual environments. Students also consider the consequences of bullying, harassment, and violent behaviour and examine ways of preventing or responding to it.

Expectations relating to substance use, addictions, and related behaviour introduce them to linkages with mental health and stress, expand their understanding of the personal and social consequences of addictions, and examine how concerns with body image, which are very prevalent at this age, can lead to problematic substance use.

The Growth and Development expectations from the 1998/2005 curriculum document focus on age-appropriate questions related to human sexuality. Students have opportunities to

explore the physical, emotional, interpersonal, and spiritual aspects of healthy sexuality, and to develop the communication skills they need to express their concerns and feelings in these areas. They also learn to identify local sources of support related to sexuality and sexual health. Students are expected to develop an understanding of reproductive systems, the possible consequences of risky behaviours, pregnancy and disease prevention, and abstinence as a positive choice for adolescents (MEDU, 2010b, p.167-8).

### **Strand C– Healthy Living**

The Healthy Living strand helps students develop an understanding of the factors that contribute to healthy development, a sense of personal responsibility for lifelong health, and a respect for their own health in relation to others and the world around them. Students will develop health literacy as they acquire the knowledge and skills they need to develop, maintain, and enjoy healthy lifestyles as well as to solve problems, make decisions, and set goals that are directly related to their personal health and well-being. Learning how to establish, monitor, and maintain healthy relationships is a key part of this strand.

The focus of the learning in this strand is not merely on health knowledge but rather on higher-level thinking connected to the application of skills for healthy living. Students are learning about health broadly as a resource for living. The emphasis is on why they are learning about healthy living and on what they need to understand about growing and healthy development in order to make informed personal choices and take responsibility for their health now and for the rest of their lives. They are also encouraged to make connections beyond themselves to understand how their health is connected with that of others and is affected by factors in the world around them.

Current thinking views health as a holistic phenomenon, and students are therefore encouraged to make connections between various aspects of their well-being, including physical, mental, emotional, spiritual, and social aspects. Health professionals also recognize that an emphasis on health promotion will pay greater dividends over the long run than an emphasis on disease treatment alone. For that reason there is a significant stress in the curriculum on learning about the connections between healthy choices, active living, and chronic disease prevention.

Living skills are also tightly linked to this strand. Because students in elementary school are still developing their sense of self, learning to interact positively with others, and learning to make connections with the broader world, it is important that they acquire strategies for coping, adapting, and managing, for communicating and relating positively to others, and for thinking critically and creatively when making life choices and responding to the world around them. The learning in this strand provides many opportunities for students to learn how to limit risk and to build the protective factors that will increase their resilience as they confront life's challenges.

The healthy living framework provides an opportunity for learning about different health topics, which can be reinforced from different perspectives and with different foci as students learn and grow, thus providing opportunities for recursive learning at different ages and stages. Students are encouraged to make connections between concepts in different content areas. If, for example, students learn refusal strategies when choosing not to smoke, they can learn to apply those same

strategies when making choices about taking care of their bodies or choices connected to substance use, sexual health, physical activities, and personal safety.

The specific expectations are organized around three overall expectations, which are based on the application of health knowledge, and are cross-referenced to four health content areas, as shown in the chart on page 31 (as well as in the complete Grade 1–8 learning summary chart in the Appendix). This organization provides teachers with the option of using either a “vertical learning” approach, in which the overall expectations are the central organizing element and specific health content is linked to them, or a “horizontal learning” approach, in which instruction is organized around the health content areas but still captures the application emphasis of the overall expectations.

Some topics within the Healthy Living strand can be challenging to teach because of their personal nature and their connection to family, religious, or cultural values. These topics can include but are not limited to human development and sexual health, mental health, body image, substance abuse, violence, harassment, child abuse, gender identity, sexual orientation, illness (including HIV/AIDS), and poverty. These topics must be addressed with sensitivity and care. It is important that both teachers and learners have a comfort level with these topics so that information can be discussed openly, honestly, and in an atmosphere of mutual respect.

When addressing all topics, but especially ones that can be challenging to talk about, it is important to give students an opportunity to explore all sides of the issue to promote understanding. Facts need to be projected objectively and students given the information they need to make informed decisions. Topics that can be challenging to talk about are best taught through discussion rather than direct instruction. It is important to set ground rules so that the discussion takes place within a setting that is accepting, inclusive, and respectful of all (MEDU, 2010b, p. 29-31).

### **Human Development and Sexual Health.**

Human development and sexual health education is more than simply teaching young people about the anatomy and physiology of reproduction. Learning about healthy development, including sexual development, requires an understanding of sexual health in its broadest context – sexual development, reproductive health, interpersonal relationships, affection, abstinence, choice and sexual readiness, protection, body image, and gender roles and expectations. Acquiring information and skills and developing attitudes, beliefs, and values related to identity and relationships are lifelong processes. The overall and specific expectations in this strand are age-appropriate and should be addressed with sensitivity and respect for individual differences. Students need to have relevant information about health topics before they reach an age at which they need to make decisions pertaining to those topics. Where possible, opportunities should be provided for both segregated and coeducational instruction (MEDU, 2010b, p33).

**GROWTH AND DEVELOPMENT- Interim Edition (MEDU, 1998/2005; 2010b)  
Grade 1 (p. 83)**

### **OVERALL EXPECTATION**

- identify the stages in development of humans (e.g., comparing physical changes from birth to childhood) and of other living things.

**SPECIFIC EXPECTATIONS**

- describe simple life cycles of plants and animals, including humans;
- recognize that rest, food, and exercise affect growth;
- identify the major parts of the body by their proper names.

**HUMAN DEVELOPMENT AND SEXUAL HEALTH – Unedited Edition (MEDU, 2010a)  
Grade 1 (p. 81-3)**

**SPECIFIC EXPECTATIONS**

- identify body parts, including genitalia (e.g., penis, testicles, vagina, vulva), using correct terminology;
- identify the five senses and describe how each functions;
- demonstrate and understanding and apply proper hygienic procedures for protecting their own health and preventing transmission of disease to others (e.g., washing hands with soap, using a tissue, sleeve sneezing, brushing and flossing teeth, not sharing hats and hairbrushes).

**GROWTH AND DEVELOPMENT- Interim Edition (MEDU, 1998/2005; 2010b)  
Grade 2 (p. 98)**

**OVERALL EXPECTATION**

- describe parts of the human body, the functions of these parts, and behaviours that contribute to good health.

**SPECIFIC EXPECTATIONS**

- distinguish the similarities and differences between themselves and others (e.g., in terms of body size or gender);
- describe how germs are transmitted and how this relates to personal hygiene (e.g., using tissues, washing hands before eating);
- identify the five senses and describe how each functions.

**HUMAN DEVELOPMENT AND SEXUAL HEALTH – Unedited Edition (MEDU, 2010a)  
Grade 2 (p. 96-7)**

**SPECIFIC EXPECTATIONS**

- outline the basic stages of human development (e.g., infant, child, adolescent, adult, older adult) and related bodily changes, and identify factors that are important for healthy growth and living throughout life;
- demonstrate an understanding of and apply practices that contribute to the maintenance of good oral health (e.g., brushing, flossing, going to the dentist regularly for a checkup).

**GROWTH AND DEVELOPMENT- Interim Edition (MEDU, 1998/2005; 2010b)**  
**Grade 3 (p. 112)**

**OVERALL EXPECTATIONS**

- describe the relationship among healthy eating practices, healthy active living, and healthy bodies;
- outline characteristics in the development and growth of humans from birth to childhood.

**SPECIFIC EXPECTATIONS**

- outline the basic human and animal reproductive processes (e.g., the union of egg and sperm);
- describe basic changes in growth and development from birth to childhood (e.g., changes to teeth, hair, feet, and height).

**HUMAN DEVELOPMENT AND SEXUAL HEALTH – Unedited Edition (MEDU, 2010a)**  
**Grade 3 (p. 109-12)**

**SPECIFIC EXPECTATIONS**

- identify the characteristics of healthy relationships (e.g., accepting differences, being inclusive, communicating openly, listening, showing mutual respect and caring, being honest) and describe ways of overcoming challenges (e.g., bullying, exclusion, peer pressure, abuse) in a relationship;
- identify factors (e.g., sleep, food, physical activity, heredity, environment, support from a caring adult, sense of belonging, peer influence) that affect physical development (e.g., of hair, skin, teeth, body size and shape) and/or emotional development (e.g., of self-awareness, adaptive skills, social skills);
- describe how visible differences (e.g., skin, hair, and eye colour, facial features, body size and shape, physical aids or different physical abilities, clothing, possessions) and invisible differences (e.g., learning abilities, skills and talents, personal or cultural values and beliefs, gender identity, sexual orientation, family background, personal preferences, allergies and sensitivities) make each person unique, and identify ways of showing respect for differences in others.

**GROWTH AND DEVELOPMENT- Interim Edition (MEDU, 1998/2005; 2010b)**  
**Grade 4 (p. 132)**

**OVERALL EXPECTATIONS**

- explain the role of healthy eating practices, physical activity, and heredity as they relate to body shape and size;
- identify the physical, interpersonal, and emotional aspects of healthy human beings.

**SPECIFIC EXPECTATIONS**

- describe the four stages of human development (infancy, childhood, adolescence, and adulthood) and identify the physical, interpersonal, and emotional changes appropriate to their current stage;
- identify the characteristics of healthy relationships (e.g., showing consideration of others' feelings by avoiding negative communication);
- identify the challenges (e.g., conflicting opinions) and responsibilities in their relationships with family and friends.

**HUMAN DEVELOPMENT AND SEXUAL HEALTH – Unedited Edition (MEDU, 2010a)  
Grade 4 (p. 129-31)****SPECIFIC EXPECTATIONS**

- describe the physical changes that occur in males and females at puberty (e.g., growth of body hair, breast development, changes in voice and body size, production of body odour, skin changes) and the emotional and social impacts that may result from these changes;
- demonstrate an understanding of personal care needs and the application of personal hygienic practices associated with the onset of puberty (e.g., increased importance of regular bathing/showering and regular clothing changes; use of hygiene products; continuing importance of regular hygiene practices, including hand washing, oral health care, and care of prosthetic devices and residual limbs).

**GROWTH AND DEVELOPMENT- Interim Edition (MEDU, 1998/2005; 2010b)  
Grade 5 (p. 147)****OVERALL EXPECTATION**

- describe physical, emotional, and interpersonal changes associated with puberty

**SPECIFIC EXPECTATIONS**

- identify strategies to deal positively with stress and pressures that result from relationships with family and friends;
- identify factors (e.g., trust, honesty, caring) that enhance healthy relationships with friends, family, and peers;
- describe the secondary physical changes at puberty (e.g., growth of body hair, changes in body shape);
- describe the processes of menstruation and spermatogenesis;
- describe the increasing importance of personal hygiene following puberty.

**HUMAN DEVELOPMENT AND SEXUAL HEALTH – Unedited Edition (MEDU, 2010a)  
Grade 5 (p. 144-6)**

**SPECIFIC EXPECTATIONS**

- identify the parts of the reproductive system, and describe how the body changes during puberty;
- describe the processes of menstruation and spermatogenesis, and explain how these processes relate to reproduction;
- describe emotional and interpersonal stresses related to puberty (e.g., questions about changing bodies and feelings, adjusting to changing relationships, crushes and more intense feelings, conflicts between personal desires and cultural teachings and practices), and identify strategies that they can apply to manage stress, build resilience, and enhance their mental health and emotional well-being (e.g., being active, writing feelings in a journal, accessing information about their concerns, taking action on a concern, talking to a trusted peer or adult, breathing deeply, seeking cultural advice from elders).

**GROWTH AND DEVELOPMENT- Interim Edition (MEDU, 1998/2005; 2010b)  
Grade 6 (p. 163)****OVERALL EXPECTATION**

- identify the major parts of the reproductive system and their functions and relate them to puberty.

**SPECIFIC EXPECTATIONS**

- relate the changes at puberty to the reproductive organs and their functions;
- apply a problem-solving/decision-making process to address issues related to friends, peers, and family relationships.

**HUMAN DEVELOPMENT AND SEXUAL HEALTH – Unedited Edition (MEDU, 2010a)  
Grade 6 (p.160-4)****SPECIFIC EXPECTATIONS**

- identify factors that affect the development of a person’s self-concept (e.g., environment, evaluations by significant others, stereotypes, awareness of strengths and needs, social competencies, cultural and gender identity, support, body image, mental health and emotional well-being, physical abilities);
- describe how they can build confidence and lay a foundation for healthy relationships by acquiring a clearer understanding of the physical, social, and emotional changes that occur during adolescence (e.g., physical: voice changes, skin changes, body growth; social: changing social relationships, increasing influence of peers; emotional: increased intensity of feelings, new interest in relationships with boys or girls, confusion and questions about changes);
- make informed decisions that demonstrate respect for themselves and others and help to build healthier relationships, using a variety of living skills (e.g., personal and interpersonal skills; critical and creative thinking skills; following First Nation, Métis, and Inuit cultural teachings, such as medicine wheel teachings connected to the four colour or seven grandfather teachings, or other cultural teachings);

- assess the effects of stereotypes, including homophobia and assumptions regarding gender roles and expectations, sexual orientation, race, ethnicity or culture, mental health, and abilities, on an individual's self-concept, social inclusion, and relationships with others, and propose appropriate ways of responding to and changing assumptions and stereotypes.

**GROWTH AND DEVELOPMENT- Interim Edition (MEDU, 1998/2005; 2010b)**  
**Grade 7 (p. 184)**

**OVERALL EXPECTATION**

- describe age-appropriate matters related to sexuality (e.g., the need to develop good interpersonal skills, such as the ability to communicate effectively with the opposite sex).

**SPECIFIC EXPECTATIONS**

- explain the male and female reproductive systems as they relate to fertilization;
- distinguish between the facts and myths associated with menstruation, spermatogenesis, and fertilization;
- identify the methods of transmission and the symptoms of sexually transmitted diseases (STDs), and ways to prevent them;
- use effective communication skills (e.g., refusal skills, active listening) to deal with various relationships and situations;
- explain the term *abstinence* as it applies to healthy sexuality;
- identify sources of support with regard to issues related to healthy sexuality (e.g., parents/guardians, doctors).

**HUMAN DEVELOPMENT AND SEXUAL HEALTH – Unedited Edition (MEDU, 2010a)**  
**Grade 7 (p.183-8)**

**SPECIFIC EXPECTATIONS**

- explain the importance of having a common understanding with a partner about delaying sexual activity until one is older (e.g., choosing to abstain from any genital contact; choosing to abstain from having vaginal or anal intercourse; choosing to abstain from having oral-genital contact), the reasons for not engaging in sexual activity, and the need to communicate clearly with each other when making decisions about sexual activity in the relationship;
- identify common sexually transmitted infections (STIs), and describe their symptoms;
- identify ways of preventing STIs, including HIV, and/or unintended pregnancy, such as delaying first intercourse and other sexual activities until a person is older and using condoms consistently if and when a person becomes sexually active;
- demonstrate an understanding of physical, emotional, social, and psychological factors that need to be considered when making decisions related to sexual health (e.g., sexually transmitted infections [STIs], possible contraceptive side effects, pregnancy, protective value of vaccinations, social labelling, gender identity, sexual orientation, self-concept issues, relationships, desire, pleasure, cultural teachings);
- explain how relationships with others (e.g., family, peers) and sexual health may be affected by

the physical and emotional changes associated with puberty (e.g., effect of physical maturation and emotional changes on family relationships, interest in intimate relationships and effect on peer relationships, risk of STIs and/or pregnancy with sexual contact).

**GROWTH AND DEVELOPMENT- Interim Edition (MEDU, 1998/2005; 2010b)**  
**Grade 8 (p. 201)**

**OVERALL EXPECTATIONS**

- identify the physical, emotional, interpersonal, and spiritual aspects of healthy sexuality (e.g., respect for life, ethical questions in relationships, contraception);
- identify local support groups and community organizations (e.g., public health offices) that provide information or services related to health and well-being;
- apply living skills (e.g., decision-making, problem-solving, and refusal skills) to respond to matters related to sexuality, drug use, and healthy eating habits.

**SPECIFIC EXPECTATIONS**

- explain the importance of abstinence as a positive choice for adolescents;
- identify symptoms, methods of transmission, prevention, and high-risk behaviours related to common STDs, HIV, and AIDS;
- identify methods used to prevent pregnancy;
- apply living skills (e.g., decision-making, assertiveness, and refusal skills) in making informed decisions, and analyze the consequences of engaging in sexual activities and using drugs;
- identify sources of support (e.g., parents/guardians, doctors) related to healthy sexuality issues.

**HUMAN DEVELOPMENT AND SEXUAL HEALTH – Unedited Edition (MEDU, 2010a)**  
**Grade 8 (p.201-5)**

**SPECIFIC EXPECTATIONS**

- identify and explain factors that can affect an individual’s decisions about sexual activity (e.g., previous thinking about reasons to wait, including making a choice to delay sexual activity and establishing personal limits; perceived personal readiness; peer pressure; desire; curiosity; self-concept; awareness and acceptance of gender identity and sexual orientation; legal concerns; awareness of health risks, including risk of STIs and blood-borne infections; concerns about risk of pregnancy; use of alcohol or drugs; personal or family values; religious beliefs; cultural teachings; access to information; media messages), and identify sources of support regarding sexual health (e.g., a health professional [doctor, nurse, public health practitioner], a community elder, a teacher, a religious leader, a parent or other trusted adult, a reputable website);
- demonstrate an understanding of gender identity (e.g., male, female, two-spirited, transgendered, transsexual, intersex) and sexual orientation (e.g., heterosexual, gay, lesbian, bisexual), and identify factors that can help individuals of all identities and orientations develop a positive selfconcept;
- develop their understanding about sexual health (e.g., about issues such as abstinence; the

choice to delay first intercourse; setting sexual limits; safer sex and pleasure; use of contraception, including condoms, for pregnancy and STI prevention), using knowledge of self and of safe-sex practices and contraception (including condom use), seeking additional information and support as needed, and practising (e.g., through role play) the communication, assertiveness, and refusal skills that may be needed for decision making in real-life contexts;

- analyse the attractions and benefits associated with being in a relationship (e.g., support, understanding, camaraderie, pleasure), as well as the benefits, risks, and drawbacks that relationships involving different degrees of sexual intimacy can pose for themselves and others (e.g., hurt when relationships end or trust is broken; in more sexually intimate relationships, risk of STIs and related risk to future fertility, unintended pregnancy, sexual harassment and exploitation; potential for dating violence).

## **Appendix Y: Sexuality Contents of the Ontario Curriculum, Grades 9 to 12: Healthy Living & Healthy Growth and Sexuality**

**(MEDU, 1999; MEDU, 2000)**

### **Grade 9 (p. 10)**

#### **OVERALL EXPECTATIONS**

- identify the factors that contribute to positive relationships with others;
- explain the consequences of sexual decisions on the individual, family, and community;

#### **SPECIFIC EXPECTATIONS**

- identify the developmental stages of sexuality throughout life;
- describe the factors that lead to responsible sexual relationships;
- describe the relative effectiveness of methods of preventing pregnancies and sexually transmitted diseases (e.g., abstinence, condoms, oral contraceptives);
- demonstrate understanding of how to use decision-making and assertiveness skills effectively to promote healthy sexuality (e.g., healthy human relationships, avoiding unwanted pregnancies and STDs such as HIV/AIDS);
- demonstrate understanding of the pressures on teens to be sexually active;
- identify community support services related to sexual health concerns.

### **Grade 10 (p.15)**

#### **OVERALL EXPECTATIONS**

- explain strategies to promote positive lifestyle choices and relationships with others;
- demonstrate understanding of the factors affecting human sexuality as it relates to themselves and others;
- demonstrate understanding of the issues and coping

#### **SPECIFIC EXPECTATIONS**

- describe environmental influences on sexuality (e.g., cultural, social, and media influences);
- explain the effects (e.g., STDs, HIV/AIDS) of choices related to sexual intimacy (e.g., abstinence, using birth control);
- identify available information and support services related to sexual health concerns;
- demonstrate understanding of how to use decision-making skills effectively to support choices related to responsible sexuality.

### **Grade 11 (p.11)**

#### **OVERALL EXPECTATIONS**

- demonstrate an understanding of sexual and reproductive health;
- demonstrate, in a variety of settings, the knowledge and skills that reduce risk to personal safety;
- describe the influence of mental health on overall well-being.

#### **SPECIFIC EXPECTATIONS**

- describe factors (e.g., environmental, hormonal, nutritional) affecting reproductive health in males and females;

- demonstrate an understanding of causes and issues related to infertility;
- demonstrate the skills needed to sustain honest, respectful, and responsible relationships;
- describe sources of information on and services related to sexual and reproductive health;
- assess reproductive and sexual health care information and services.

**Grade 12** (p. 22)

**OVERALL EXPECTATIONS**

- describe how society and culture affect individual perceptions and expressions of sexuality;
- demonstrate an understanding of strategies that promote personal safety and prevent injuries;
- demonstrate an ability to use specific strategies to enhance their own mental health and that of others;
- demonstrate an understanding of strategies that promote healthy relationships.

**SPECIFIC EXPECTATIONS**

- analyze the factors (e.g., culture, media) that affect gender roles and sexuality;
- demonstrate an understanding of the factors (e.g., attitudes, values, and beliefs about gender roles and sexuality) that affect the prevention of behaviour related to STDs, AIDS, and pregnancy;
- describe the factors (e.g., healthful eating, abstinence from smoking and alcohol) that contribute to healthy pregnancy and birth;
- describe the characteristics of healthy, respectful, and long-lasting relationships;
- assess the skills needed to maintain healthy, respectful, and long-lasting relationships;
- describe the communication skills needed to discuss sexual intimacy and sexuality in a relationship.

**Appendix Z: Key Concepts and Topics of Comprehensive Sexuality Education**  
(SIECUS, 2004)

**Key Concept 1: Human Development**

- Topic 1:** Reproductive and Sexual Anatomy and Physiology
- Topic 2:** Puberty
- Topic 3:** Reproduction
- Topic 4:** Body Image
- Topic 5:** Sexual Orientation
- Topic 6:** Gender Identity

**Key Concept 2: Relationships**

- Topic 1:** Families
- Topic 2:** Friendship
- Topic 3:** Love
- Topic 4:** Romantic Relationships and Dating
- Topic 5:** Marriage and Lifetime Commitments
- Topic 6:** Raising Children

**Key Concept 3: Personal Skills**

- Topic 1:** Values
- Topic 2:** Decision-making
- Topic 3:** Communication
- Topic 4:** Assertiveness
- Topic 5:** Negotiation
- Topic 6:** Looking for Help

**Key Concept 4: Sexual Behavior**

- Topic 1:** Sexuality Throughout Life
- Topic 2:** Masturbation
- Topic 3:** Shared Sexual Behavior
- Topic 4:** Sexual Abstinence
- Topic 5:** Human Sexual Response
- Topic 6:** Sexual Fantasy
- Topic 7:** Sexual Dysfunction

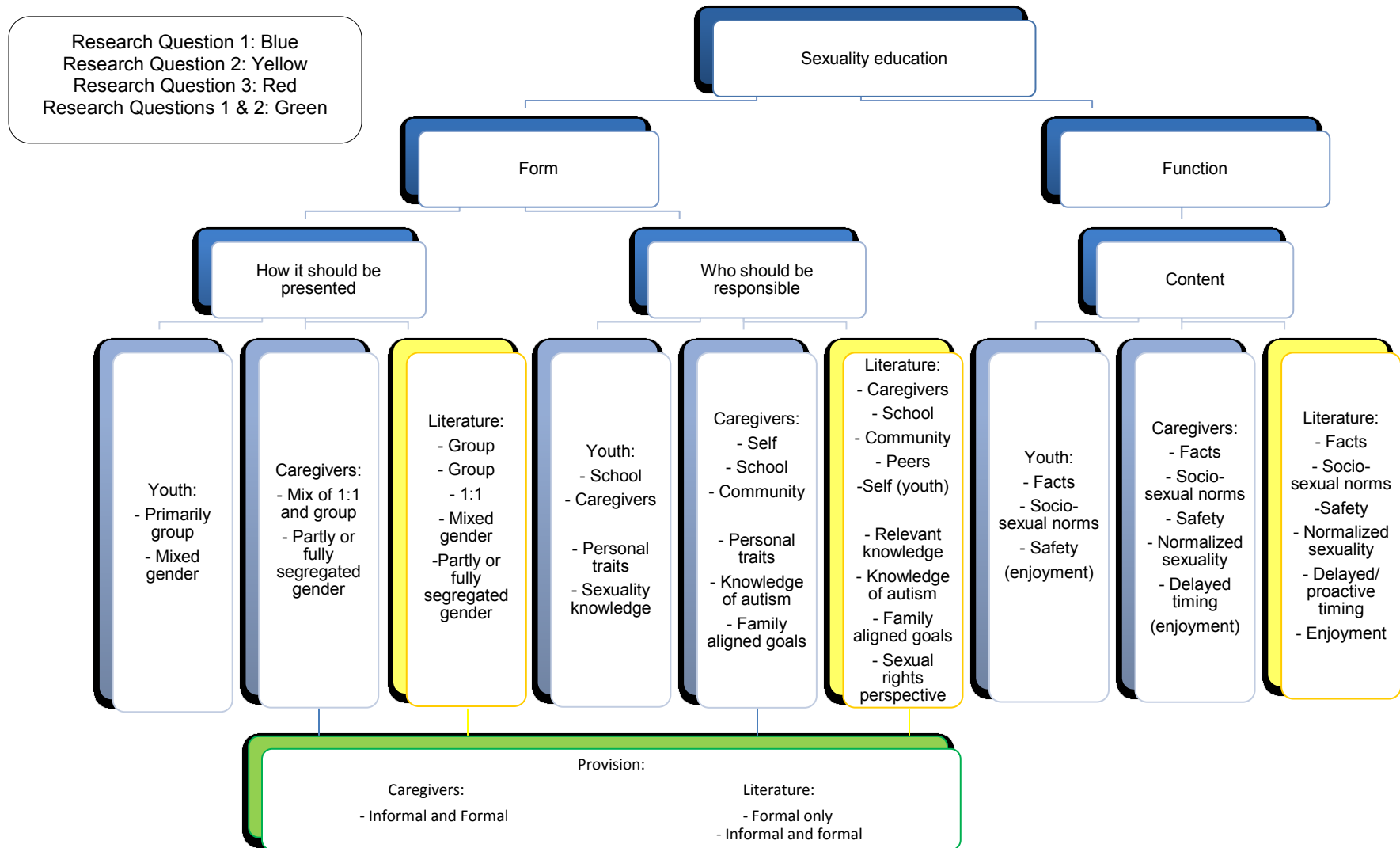
**Key Concept 5: Sexual Health**

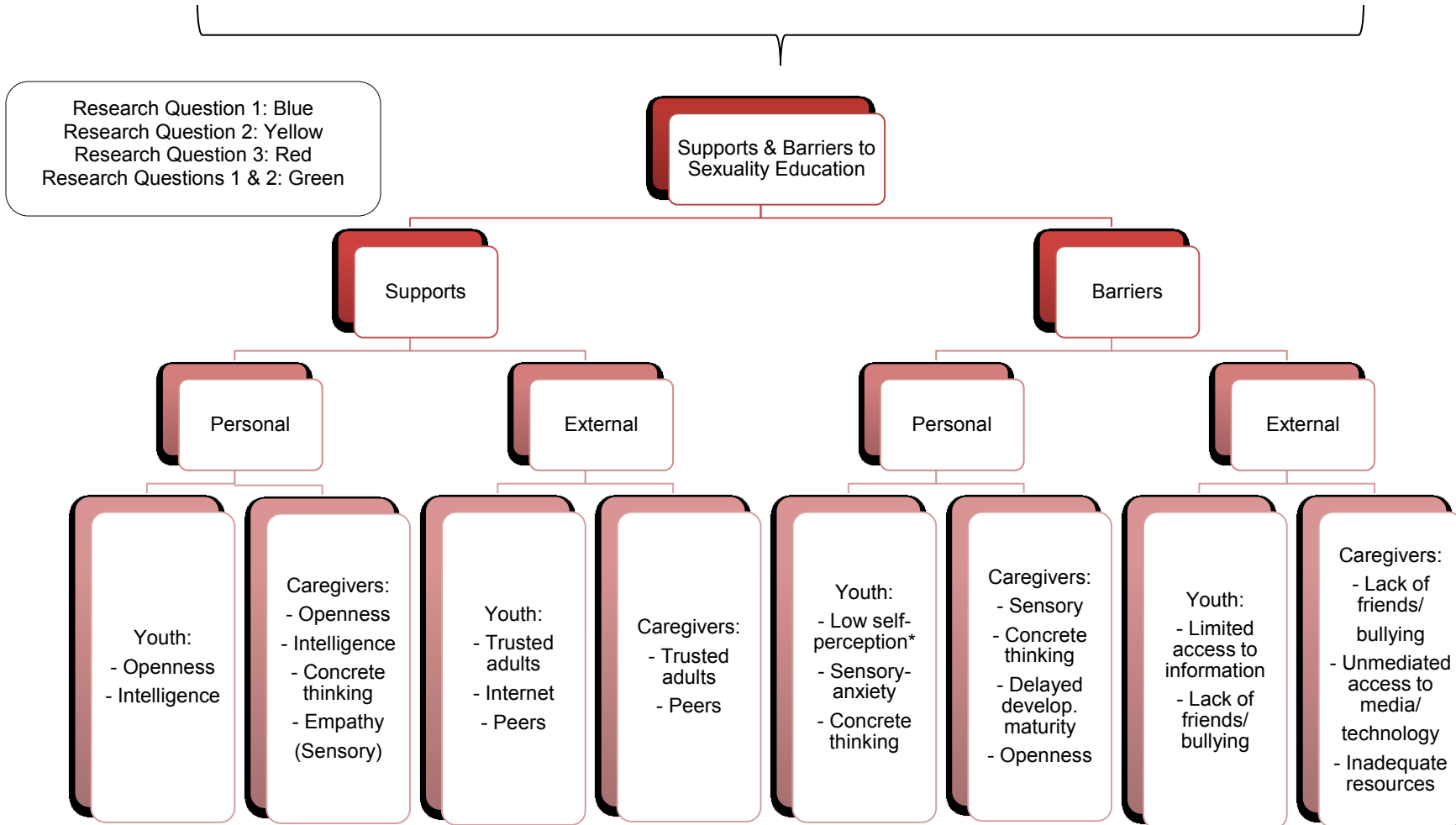
- Topic 1:** Reproductive Health
- Topic 2:** Contraception
- Topic 3:** Pregnancy and Prenatal Care
- Topic 4:** Abortion
- Topic 5:** Sexually Transmitted Diseases
- Topic 6:** HIV and AIDS
- Topic 7:** Sexual Abuse, Assault, Violence, and Harassment

**Key Concept 6: Society and Culture**

- Topic 1:** Sexuality and Society
- Topic 2:** Gender Roles
- Topic 3:** Sexuality and the Law
- Topic 4:** Sexuality and Religion
- Topic 5:** Diversity
- Topic 6:** Sexuality and the Media
- Topic 7:** Sexuality and the Arts

## Appendix AA: Visual Representation of Completed Conceptual Framework with Linkages to Research Questions





**Appendix BB: Summary of Complete Findings**

*Table BB1*  
Summary of Complete Findings

	Finding	Youth interview	Caregiver interview	RESEARCH QUESTION 2			Final finding	
				Extant textual evidence <sup>a</sup>				
				Literature	Policy	Curricula		
<b>RESEARCH QUESTION 1</b>	<b>Finding 1: Form</b>						<b>Final Finding 3</b>	
	Responsibility	Caregivers	7/9	11/11	Strong	Strong	Strong	Sexuality education provided primarily by caregivers, supported by school and community partners.
		School	8/9	11/11	Strong	Strong	Strong	
		Community partners	1/9	11/11	Strong	Strong	Strong	
		Peers	1/9	0/11	Moderate	Moderate	Moderate	
		Self	--	--	Moderate	Moderate	Moderate	
	Educator attributes	Personal traits	8/9	10/11	Lacking	Lacking	Moderate	<b>Final Finding 3</b>
		Experience	7/9	0/11	Strong	Strong	Strong	Trustworthiness; Relevant experience; Knowledge of autism; Goals/delivery determined with family
		Knowledge of autism	--	10/11	Strong	Lacking	Moderate	
		Alignment of goals	0/9	5/11	Strong	Lacking	Moderate	
		Rights perspective	--	--	Moderate	Moderate	Lacking	
	Provision	Group only	6/9	0/11	Lacking	Lacking	Moderate	<b>Final Finding 4</b>
		Mix of group & 1:1	3/9	10/11	Moderate	Lacking	Moderate	Individualized goals provided in individual/group setting; Mixed gender unless evidence otherwise; Separate formalized education targeted to disorder
		Individual	0/9	0/11	Strong (goals)	Moderate	Lacking	
		Single Gender	0/9	10/11	Moderate	Lacking	Moderate	
Mixed gender		6/9	0/11	Lacking	Lacking	Moderate		

	Diagnosis	--	10/11	Strong	Lacking	Moderate	<b>Final Finding 1</b>	<b>Final Finding 2</b>
	<b>Finding 2: Content</b>							
	Facts	6/9	11/11	Strong	Strong	Strong	Facts (necessary) + socio-sexual behaviours (sufficient)	Safety + Pleasure = Normalization
	Socio-sexual behaviours/norms	7/9	11/11	Strong	Strong	Strong		
	Safety	4/9	11/11	Strong	Strong	Strong		
	Normalization	--	10/11	Strong	Strong	Strong		
	Pleasure	2/9	2/9	Strong	Strong	Strong		
	Delayed timing	--	7/11	Strong	Moderate	Moderate		
	Proactive provision	--	--	Strong	Moderate	Lacking		
	<b>Finding 3: Overarching education</b>						<b>Final Finding 4</b>	
	Formal only	--	0/11	Strong	Lacking	Moderate	Sexuality education overarching activity taking place across informal and formal settings.	
Informal only	--	0/11	Lacking	Lacking	Lacking			
Overarching	--	11/11	Strong	Moderate	Moderate			
<b>RESEARCH QUESTION 2</b>	<b>Finding 4: Extant textual evidence</b>	See above					See findings 1-4	
	Literature							
	Policy							
	Curricula							
<b>RESEARCH QUESTION 3</b>	<b>Finding 5: Individual strengths</b>						<b>Final Finding 5</b>	
	Openness	1/9	9/11	--	--	--	Some items more stable: Intelligence; Empathy; Delayed dev. maturity; Trusted adults; Adequate resources (e.g., supported technology, information,	
	Intelligence	1/9	11/11	--	--	--		
	Empathy	0/9	6/11	--	--	--		
	Concrete thinking	0/9	5/11	--	--	--		
<b>Finding 6: External supports</b>								

Trusted adult	7/9	11/11	--	--	--	curriculum); Inadequate resources (including limited info.); Bullying; Unsupported technology; Judgment
Internet	7/9	0/11	--	--	--	
Peers	3/9	5/11	--	--	--	
<b>Finding 7: Personal barriers</b>			--	--	--	Some items more fluid: Openness; Intelligence; Concrete thinking; Sensory and other particularities
Low self-perception	3/9	0/11	--	--	--	
Sensory/related issues	3/9	9/11	--	--	--	
Concrete thinking	1/9	10/11	--	--	--	
Delayed dev. maturity	0/9	10/11	--	--	--	
Openness	0/9	7/11	--	--	--	Personal strength identified countering disablist assumptions of disability (Empathy)  False personal barrier revealed (Negative self-perception)
<b>Finding 8: External barriers</b>						
Limited access to information	4/9	0/11	--	--	--	
Lack of friends/bullying	4/9	9/11	--	--	--	
Unmediated access to media/technology	0/9	10/11	--	--	--	
Inadequate resources	0/9	9/11	--	--	--	
Judgment	0/9	8/11	--	--	--	