A Bridge to Nowhere: Experiences of the Transition from High School to Adult Life for Young Adults with Intellectual Disabilities in Ontario

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Abstract

The foremost aim of this study is inherent in my primary research question which asks how the families of adult children with intellectual disabilities understand and experience the transition that takes place when their children age out of high school. In order to achieve this goal, I turned to the families themselves and asked participants to recount their lived experiences during this important transition. Throughout my data collection and subsequent analysis, I relied on methods common to interpretative phenomenology to guide my process and ensure its viability. To this end, I have conducted a phenomenological analysis of participant narratives and provide a comprehensive portrayal of how parents experience and understand the transition that takes place when their adult children with intellectual disabilities age out of school. I have strived to embed this study within the framework of the existing literature and policy pertaining to this transition. I have enhanced this research with an original content analysis of news articles pertaining to the post-school lives of adults with intellectual disabilities. Finally, I undertook interviews with community and government representatives. When taken together, these elements illustrate how difficult it is for the parents of young adults with intellectual disabilities to replace the services and supports that they lose when their adult children age out of high school in Ontario.

Dedication

The completion of this thesis has been an uphill battle which has lasted and endured through the greatest of life changes. This journey began with a seven-year deadline and ends with just moments to spare. It began in a bachelor apartment in the city with a boyfriend and an occasional teaching job and ends in a three-bedroom home in the forest with a husband, son, and career.

I owe more than can ever be repaid to my husband, and to my mother, for their unwavering support throughout this journey. Without their help and encouragement, I would undoubtedly have folded long ago. In the end, however, it was the potential disappointment of my father that propelled me ever onward. He can now, finally, plan Phd party.

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Prologue

Welcome to Holland

By Emily Pearl Kingsley

When you are going to have a baby, it's like planning a vacation trip - to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum, the Michelangelo, David, the Gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After all the months of anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes on and says "Welcome to Holland." "Holland??" you say. "What do you mean Holland? I signed up for Italy. I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there is a change in flight plan. They landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks and you must learn a whole new language. And you will meet a whole new group of people you would never have met otherwise. It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you have been there for a while you catch your breath, you look around and you begin to notice that Holland has windmills. Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy and they are bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I planned." The pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss. But if you spend your life mourning about the fact that you didn't get to Italy, you may never be free to enjoy the very special, the lovely things about Holland (Kingsley, 1998).

These poignant words were written by Emily Pearl Kingsley in 1987 and have been re-published multiple times. Having been asked to describe the experience of raising a child with a disability, Welcome to Holland, represents Kingsley's attempt to help people to understand and imagine how it might feel to have and raise a child with a disability. Kingsley's essay was given to me by a participant in this research. She described how important Kingsley's words were to her and noted that she regularly shares the essay with those on a similar journey and those on the outside who are trying to understand it.

Chapter One: Introduction

Every Canadian child, regardless of ability, is entitled to receive a government-funded public education. Children are guaranteed this right by several pieces of international legislation. These include the *International Covenant on Economic, Social and Cultural Rights* (1966), the *Convention on the Rights of the Child* (1989) and the *United Nations' Declaration of the Rights of Persons with Disabilities* (2006) (Towle, 2015). In Canada, education comes under provincial and territorial jurisdiction and the age at which a young adult must leave school varies slightly across the country. In Ontario, students become ineligible for school-based services on the last school day in June in the year in which they turn 21 (Ontario Education Act, 1990, 33:1). The vast majority of young adults have little difficulty completing high school within this timeframe. Individuals with severe intellectual disabilities, however, typically stay in school until they are deemed too old for school-based services (Sanford et al., 2011; Strong, 2018). As such, the term 'age out' is commonly used to refer to the termination of individual special education services offered by the province when students reach 21 years of age (Sanford et al., 2011).

Publicly funded school boards in Ontario are provided with numerous government publications and roadmaps designed to assist with the delivery of effective transition planning intended to facilitate a workable transition from school to post-school life for students with disabilities (Ontario Ministry of Education, 2000, 2002, 2004, 2017, 2018). Despite these numerous publications, a 2016 report by the Ontario Ombudsman titled, *Nowhere to Turn*, investigated more than 1,400 complaints from families of young adults with intellectual disabilities. This report highlights Ontario's systemic failure to help desperate families who find themselves struggling to care for their adult relatives with intellectual disabilities (Dubé, 2016).

Under Ontario’s Education Act, the Ministry of Education is responsible for ensuring that all children with exceptionalities have access to appropriate special education programs and services without payment of fees (Ontario Education Act, 1990). However, these services come to an abrupt end the year students turn 21. Along with losing these services, exceptional students and their families also lose the custodial support provided by the school system. Mageou (2011) notes that the custodial function of schools is one of the most important responsibilities of public education. She contends that, aside from education, schools provide physical guardianship of children, which allows their parents to work, and thereby functions as an irreplaceable aspect of our economy. While the parents of typically developing children rely less and less on the custodial function of school as their children grow and mature, the parents of adult children with severe intellectual disabilities continue to require this type of support.

Transition planning in Ontario schools is intended to help exceptional students make a successful transition from school to work, further education, or community living (Ontario Ministry of Education, 2002). Theoretically, transition planning is meant to address many of the challenges that are currently faced by Ontario families. With this study, I entered into a phenomenological exploration of the lived realities faced by the parents of children with intellectual disabilities as they navigate life after high school. Conducting a phenomenological study allowed me to delve into the perceptions, perspectives, and understandings of parents who have experienced this transition. I accomplished this using in-depth interviews conducted with a small sample of participants. My research focusses on commonalities and provides a composite description of the essence of the experience of the transition to post-school life as faced by the families of individuals with intellectual disabilities in Ontario.

The services and supports available to adult children with intellectual disabilities who have aged out of high school are provided by both the provincial and federal governments. As such, an analysis of disability legislation and policy in Canada and Ontario has been included in this study. Further, the research presented here is supplemented by a content analysis of news articles concerning the post-school lives of adults with intellectual disabilities compiled from the *Canadian Broadcasting Corporation* (CBC) and the *Toronto Star*. Bowen (2009) contends that documents, such as media texts, can provide context, additional questions, supplementary data, a means of tracking change and can verify the findings from other data sources. Hence, this thesis provides a retrospective examination of the Ontario media's coverage of, and portrayal of, the needs of adults with intellectual disabilities and their families.

Although Ontario has strong transition planning policies, there is very little research regarding the effectiveness and outcomes of these policies for exceptional students and their families. This study does not purport to provide to fill this gap. It does, however, provide a reflective analysis of the process and outcomes for students who have recently graduated. I anticipate that this research may therefore provide a foundation for future studies to explore the longer-term impacts of Ontario's transition planning for exceptional students.

In the following sections of this chapter I will clarify the various definitions associated with my research and discuss special education, legislation, policy and transition planning as it relates to Ontario. From that grounding point, I will define my research questions and outline my background and personal interest in this research. I will conclude this chapter with a rationale explaining why I decided not to undertake emancipatory or participatory research but, instead, chose to hear the various stories of transition from the voices of the parents of exceptional young adults.

Definitions

Disability is a multidimensional concept with both objective and subjective characteristics which makes it difficult to define (Office for Disability Issues, 2003). Article one of the *United Nations Convention on the Rights of Persons with Disabilities* provides a comprehensive, and often referenced, definition of disability. In this Convention, persons with disabilities are defined as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, Article 1, para. 2). While persons with physical impairments are likely to face challenges upon the completion of high school, this research focusses exclusively on the experiences of families with adult children with intellectual disabilities. Thus, it is important to further define disability as it relates to this study.

According to the US Department of Health and Human Services (2016), "intellectual and developmental disabilities are disorders that are usually present at birth and that negatively affect the trajectory of the individual's physical, intellectual, and/or emotional development" (para. 1). Accordingly, the terms intellectual and developmental disability are often used interchangeably. However, the terms are not true synonyms. An intellectual disability is characterized by problems with intellectual functioning (such as learning, problem solving and judgement) and adaptive functioning (such as everyday social and life skills), while a developmental disability can be intellectual, physical or both (American Psychiatric Association, 2018; US Department of Health and Human Services, 2006). The use of the term intellectual disability in this thesis is therefore intended to denote limitations in intellectual and adaptive functioning.

According to the Ontario Ministry of Education (2018), “some students have educational needs that cannot be met through regular instructional and assessment practices” (para. 1). The needs of these students are met “through accommodations, and/or an educational program that is modified above or below the age-appropriate grade level expectations for a particular subject or course” (Ontario Ministry of Education, 2018, para. 1). Students who require significant modification are typically identified as exceptional pupils. As defined by the Ontario Education Act (1990), an exceptional pupil is one “whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program” (subsection 1). Thus, students with intellectual disabilities are identified by the Ontario Ministry of Education as exceptional pupils. A more thorough review of the clinical characteristics of intellectual disability will be presented in the following chapter.

Special Education, Legislation and Policy in Canada

The education system in Canada differs from many other developed countries in that individual provinces and territories, rather than the federal government, hold responsibility for the legislation and policy related to education. The *Constitution Act* of 1867 assigned educational responsibility exclusively to the provincial legislatures and, even today, Canada has no federal office of education (Leslie & Peters, 2015). Instead, each jurisdiction has a Ministry of Education which is responsible for its own Education or School Act (McBride, 2013). However, while provincial autonomy relative to education is constitutionally acknowledged, it would be a mistake to overlook the role played by the federal government in shaping provincial education policy. Of importance to this research is the influence that the federal government has had on special education policy in Canada. Until the *Canadian Charter of Rights and Freedoms* was established in 1982, there were no clearly defined rights for students with special needs. Given this, there was no constitutional basis upon which the rights of children with special needs could be advocated. Nova Scotia was the first province to initiate mandatory legislation for special education students, followed by Saskatchewan in 1971 and Ontario in 1980 (McBride, 2013). Other provinces followed suit in various ways but there was no formal mandate to enact special education legislation until Section 15 of the Charter, which concerns equality rights, came into effect in 1985. Section 15 required that all provincial legislation, including educational legislation, guarantee equality rights and protection under the law. Thus, the Charter provided the "impetus for legislation to ensure equality of access to public education for all children of school age and to encourage the further development of provincial legislation, policies, and guidelines to actualize the process" (McBride, 2013, p. 5). As part of the Constitution of Canada, the Charter represents 'supreme' law and, therefore, all practices and decisions undertaken by Canada's educational ministries, schools and school boards must be consistent with the rights guaranteed in the Charter (School Advocacy Hamilton, 2006).

Although the Charter requires that special education law be enacted throughout Canada, there are jurisdictional differences across the country in the ways in which students receive special education services. These differences include teacher-training requirements, definitions of exceptionalities and funding models (Dworet & Bennett, 2002). However, the Charter also created several key similarities in special education services. These similarities are evident in the fact that all jurisdictions in Canada currently require some form of individualized planning and programming for students with special needs. This programming is generally referred to as an Individualized Education Plan, or IEP (Dworet & Bennett, 2002; McBride, 2013, Towle, 2015). There are many commonalities in the legislation governing IEP planning and implementation across Canada and all jurisdictions include requirements for transition planning between schools and into adulthood (McBride, 2013). Although this research includes a focus on IEP transition planning and transition outcomes in Ontario, it is anticipated that it will provide a foundation for future studies of IEP transition models across Canada.

Standards and Requirements for all IEP Transition Plans in Ontario

Standards for the development and review of individual education plans in Ontario are governed by regulation 181/98 of *the Ontario Education Act*. Regulation 181/98, s. 6(4) of this Act states that "where the pupil is 14 years of age or older, the Individual Education Plan must also include a plan for transition to appropriate post-secondary school activities, such as work, further education and community living" (Ontario Education Act, 1990). Under this regulation, principals are responsible for confirming that all transition plans are developed in consultation with a student's family and that the students themselves are involved in the planning process once they reach the age of 16; that appropriate community agencies and postsecondary institutions are consulted on the plan; that any programming recommendations made by an Identification, Placement and Review Committee or Special Educational Tribunal are considered; that the plan is completed and revised as required and a copy is sent to the parent or student, aged 16 and over, in a timely manner; and, that an updated copy of the plan is kept in the student's Ontario Student Record (Ontario Ministry of Education, 2002).

Standards for all Ontario transition plans are outlined in the Ontario Ministry of Education's 2017 policy document *Special Education in Ontario – Kindergarten to Grade 12: Policy and Resource Guide*. As stated in that document, every transition plan in Ontario must include the following elements: specific goals for the student's transition to postsecondary activities that are realistic and reflective of the strengths, needs, and interests of the student; the actions required, now and in the future, to achieve the stated goals; the persons or agencies (student, parents, educators, providers of specialized support and services, community agencies) responsible for or involved in completing, or providing assistance in completing, each of the identified actions; and timelines for the implementation of each of the identified actions (Ontario Ministry of Education, 2017).

Shearin, Roessler and Schriner (1999) used an outcome/skill checklist to evaluate the transition content of 68 IEP's for their compliance with the United States congressional mandate to include school-to-work goals and linkages in transition planning for exceptional students. Although this study addressed American policy, its findings are relevant to my research as they indicate that, despite specific regulations, IEP's remain unclear regarding residential, postsecondary and employment goals for many students. Similarly, Powers et al. (2005) analyzed the transition components of nearly 400 American IEP's and found that transition goals were often not addressed or were inadequately detailed despite specific policy mandates. Although these studies represent American IEP transition planning, they highlight a trend in transition planning non-compliance that may also be relevant in the Ontario context. Consequently, one aspect that my research explores is the ways in which Ontario families understand and experience the school based IEP transition planning process.

Defining the Research Questions

Ultimately, this study aims to explore and understand the experience of the transition to post-school life as faced by the families of individuals with intellectual disabilities. In order to achieve this goal, I turned to the families themselves and asked participants to recount their lived experiences with IEP planning, disability policy and governmental services and supports during this important transition. Further, as this study is couched in Schlossberg's 4 Ss model (situation, self, support, and strategies), I strived to ascertain the influence that these factors had on family experiences during this transition. To this end, I conducted a policy analysis of disability legislation and policy in Canada as it relates to adults with intellectual disabilities in order to understand how families experience the services and supports available to their adult children with intellectual disabilities once they age out of high school. Further, I conducted a content analysis of news articles concerning the post-school lives of adults with intellectual disabilities in order to ascertain how the news media portrays the post-school needs of adults with intellectual disabilities in Ontario. The research questions that guided the various components of this thesis are as follows:

Primary research question.

1. How do the families of adult children with intellectual disabilities understand and experience the transition that takes place when their children age out of high school?

Secondary research questions.

1. How do the families of adult children with intellectual disabilities understand and experience the school based IEP transition process?
2. How do the transition variables outlined in Schlossberg's 4 Ss model (situation, self, support, and strategies) affect the way families experience the transition that takes place when their adult children with intellectual disabilities age out of high school?
3. How do families experience disability legislation and policy in Canada and Ontario as their adult children with intellectual disabilities age out of high school?

Autobiographical Statement

I come to this research as a Special Education teacher and advocate. Although I never envisioned myself as a teacher, a thirst for travel in my early twenties led to two successful years teaching English abroad in Korea and Japan. This seminal experience was my introduction to the world of teaching and the richness of the profession. Following this experience, I returned to Canada and completed a Bachelor of Education at the University of Ottawa in 2010. I began working as a supply teacher for the Ottawa Carleton District School Board (OCDSB) shortly after completing teachers' college and quickly found steady employment as a Special Education teacher. In my relatively short career, I have taught in both mainstream and special education classrooms. I have earned a Master's degree in Education and also hold specialist qualifications in special education. Currently, I am employed by the OCDSB as a Learning Support Teacher, responsible for the overall administrative and educational needs of students with special education requirements within one elementary school.

As mandated by the Ontario Ministry of Education, the OCDSB's Special Education Plan is built on a model of inclusion, however it also recognizes that some students' needs are better met through more specialized programming (Ottawa Carleton District School Board, 2018). It was in this specialized programming, specifically as a teacher in a congregated autism classroom, that my interest in this research was born.

My greatest privilege as a teacher has been the special education classroom. I have witnessed firsthand the amount of love, time, patience, exasperation, effort, struggle, joy and frustration that go into both teaching and raising children with intellectual disabilities. My time in special education classrooms has shown me the great strength and resilience demonstrated by the parents of children who will likely not outgrow the need for the unrelenting care of their parents or other caregivers.

In my experience, the special education classroom is focused on basic numeracy, literacy and self-regulation skills. It is typically a place of love, mutual trust and endless routine. It is a place where parents believe their children will be safe, cared for and successful. However, as many good things do, a child’s time in this special place comes to an end the year they turn 21. As a teacher, I have often wondered how well we prepare our special education students and their families for this transition. As a researcher, I am interested in how the families of adult children with intellectual disabilities understand and experience the transition that takes place when their children age out of high school. I undertook this research not to validate my own beliefs, but to gain a fuller understanding and appreciation of the transition from school to post-school life as experienced by the families of adult children with intellectual disabilities.

Understanding why this Research is not Emancipatory or Participatory

Research efforts involving people with disabilities have traditionally been criticized for failing to have any meaningful effect on the services offered to participants or their overall quality of life. Research outcomes have historically been of little relevance to participants, often included distorted representations of participant experience, and typically failed to bring about positive change (Barnes & Sheldon, 2007). Thus, traditional top-down research efforts are increasingly criticized for not recognizing or valuing the needs of research participants (Cocks & Cockram, 1995; Coons & Watson 2013; Kiernan, 1999; Knox et al., 2000). To overcome this criticism, researchers have begun to seek out methodologies that allow for cooperative enquiry in which participants are involved as co-researchers who help to design, direct and analyze research studies (Kiernan, 1999). In the field of disability studies, participatory and emancipatory research models have emerged as methodologies which are seen to involve and empower research participants with disabilities.

The participatory research model is built on several key assumptions that serve to distinguish this paradigm from other research approaches. These assumptions include an acknowledgement that society creates disability and disadvantage and that a transformation of larger society is needed to counter this oppression; an understanding that exploring the actual lived experiences of disadvantaged people is vital to the emancipation and liberation of oppression; an acceptance that people have the capacity to create solutions to their own problems; a recognition of the link that exists between education and the empowerment of oppressed people; and a commitment by researchers to become actively involved in the liberation process (Cocks & Cockram, 1995; Coons & Watson 2013; Kiernan, 1999; Knox et al., 2000). A core tenet of the participatory research model is that it is collaborative research with people, rather than research on people. This model is qualitative in nature and aims to eliminate hierarchical research relationships and to engage participants in the design, conduct and evaluation of research. While relevant involvement of all research participants is paramount to the participatory research paradigm, research conducted using this method is initiated and ultimately controlled by researchers rather than participants (Gilbert, 2004; Kiernan, 1999).

Emancipatory research is similar to participatory research in its underpinnings. Both paradigms require that researchers adopt the social model of disability, rest on the tenet that people, regardless of ability, have a right to be involved in research that concerns their lives, and advocate for a more cooperative relationship between all interested parties. However, rather than a co-researcher alliance or partnership, the emancipatory paradigm argues for a complete transformation of the traditional research model in which the research participants, regardless of ability, assume control over all aspects of the research process (Chappell, 2000; Cocks & Cockram, 1995; Gilbert, 2004; Kiernan, 1999; Knox et al., 2000; Stalker, 1998; Tuffrey-Wijne & Butler, 2010). Essentially, emancipatory research requires researchers to surrender scientific neutrality, focus on political action for the benefit of people with disabilities and make themselves accountable to people with disabilities (Kiernan, 1999; McColl et al., 2013).

It is difficult to quantify the benefits of participatory and emancipatory research efforts and, therefore, to date, these methodologies have no quantifiable evidence associated with their use. That said, it can be logically assumed that the direct involvement of individuals with disabilities in research which concerns their lives stands to benefit research findings. However, this benefit does not come without its limitations. Participatory and emancipatory research models deliberately contradict the view of the expert researcher typically held within the academic community. This paradigm shift is not without contention as there is debate over the degree to which participants, who are not formally trained in research methodologies, can shape and conduct research. Tuffrey-Wijne and Butler (2010) note that, in an effort to achieve maximum inclusion, researchers have sometimes failed to differentiate between the work best undertaken by a trained researcher and that best undertaken by an untrained co-researcher. Additionally, the complete control given to participants in emancipatory studies is potentially even more problematic as this model relies on participants to carry out the same types of work that researchers typically receive extensive training to conduct (Tuffrey-Wijne & Butler, 2010). There is also debate about the degree to which people with intellectual disabilities can be involved in high quality research in a meaningful, rather than tokenistic, way (Chappell, 2000; Cocks & Cockram, 1995; Knox et al., 2000; Tuffrey-Wijne & Butler, 2010). Chappell (2000) asserts that there are inherent attitudinal and structural barriers to the full participation of people with intellectual disabilities in research. Researchers must therefore be careful to avoid a false sense of participation when conducting participatory and emancipatory research with people with intellectual disabilities as the tokenistic involvement of people with intellectual disabilities in research may serve to further exploit and dominate this already vulnerable group (Cocks & Cockram, 1995).

My original vision for this study involved the direct participation of individuals with intellectual disabilities. I have a background in special education and I am well versed in augmentative communication techniques. Thus, when I began this study, I believed that I was well equipped to interview participants with intellectual disabilities about their post school lives. After careful consideration, however, I determined that many of the concepts that I wanted to explore were abstract and retrospective. Given that intellectual disability is characterized by deficits in both of these areas (Boat & Wu, 2015; Vicari et al., 2006) I determined that excluding the voices of individuals with intellectual disabilities from this study was preferable to the token inclusion of them. I ultimately heeded the advice of the paradigm critics and opted to gather the transition stories of individuals with intellectual disabilities through the voices of their closest allies, their parents.

Chapter Two: Literature Review

Young adults with intellectual disabilities face poorer employment, postsecondary education, independent living, interpersonal relationships and community involvement outcomes than do their non-disabled peers (Janus, 2009; Newman et al., 2011; Sanford et al., 2011). After aging out of high school services, many Canadian adults with intellectual disabilities also struggle to access services, care, and housing and to navigate through the various other provincial and federal supports that are potentially available to them (L'Arche Canada, 2014). Consequently, various policy analysts have concluded that Canadian disability policy is often fragmented and incoherent (McColl et al, 2017). Ontario's 2016 Ombudsman report, *Nowhere to Turn*, indicates that Ontario is no exception in this regard and underscores the unmet needs of desperate families who find themselves struggling to manage the care of their adult relatives with intellectual disabilities (Dubé, 2016).

The Ontario Ministry of Education's website notes that transition planning in Ontario schools is intended to help exceptional students make a successful transition from school to work, further education, or community living (Ontario Ministry of Education, 2002). Theoretically, transition planning is intended to address many of the challenges that are currently being faced by Ontario families and that are poignantly detailed in the 2016 *Nowhere to Turn* report. On paper, Ontario offers significant support vehicles for young adults as they transition to post-school life. As individuals and families reach this milestone, however, the reality can be much different as they seek to replace the children's services that are no longer available to them (L'Arche Canada, 2014).

In order to provide context to the current situation that adults with intellectual disabilities and their families are facing, this chapter begins by providing an overview of the clinical definition of intellectual disability. From there, it reviews the relevant literature related to the transition planning that occurs when young adults with intellectual disabilities transition from school to post-school life. This chapter then documents the closure of residential facilities, an initiative that placed individuals with intellectual disabilities into the care of their families and communities. A brief overview of the post-school services available to young adults with intellectual disabilities in Ontario is also provided. From that position of grounding, this chapter then turns to examine the impact that providing care to a loved one with an intellectual disability has on families and caregivers. To round out the discussion on transition, included is a review of recent Canadian research into the transition faced by young adults with intellectual disabilities and their families when they age out of the school system. Finally, I end this chapter with an overview of Schlossberg's 4 Ss transition model, which I used to form the conceptual framework for this study.

Before exploring these topics, however, it should be noted that the phenomenological research that I have undertaken in this study required the use of bracketing, a technique that allows researchers to put aside their previous experiences, personal beliefs, and biases which enables them to better represent the experiences of their participants (Corby, Taggart & Cousins, 2015; Creswell, 2007; Flood 2010). The concept of bracketing is fully discussed in my methodology chapter but, at this point, it should be noted that one of the recommendations for researchers employing this technique is to delay their literature review until after data collection and analysis (Chan et al., 2003; Gearing, 2004: Streubert & Carpenter, 1999). The thesis proposal and subsequent ethics application required for this research made it impossible to fully heed this recommendation. Consequently, I undertook an initial literature review at the onset of this study. Once I completed my data collection and analysis, I modified this initial literature review to include the topics that were important to the parents I interviewed. Initially, when I designed this study, I believed that my research would focus exclusively on the transition planning practices in Ontario schools as experienced by young adults with intellectual disabilities and their families. However, parent participants were much more interested in talking about their families' daily lived realities following the loss of high school services. Consequently, this review focuses heavily on the factors that influence the post-school life of young adults with disabilities as this was a strong focus of all my participant interviews.

Intellectual Disability

The term intellectual disability refers to impairments in both cognitive functioning and adaptive skills which occur before an individual reaches adulthood (American Psychiatric Association, 2018). Individuals with intellectual disability experience delays in meeting motor, fine motor, language and/or psychosocial milestones and in acquiring the everyday adaptive skills needed to effectively take care of oneself and to interact with others (Harris, 2006). Intellectual disability is characterized by an IQ below 70 combined with significant difficulty with daily living skills. Intellectual disability has been linked to complex interactions involving genetic and environmental factors and, while not always possible, a specific cause for an intellectual disability can be determined in roughly two-thirds of cases (Harris, 2006). Of those cases where a specific cause can be determined, common genetic causes include Fragile X syndrome and Down syndrome while common differential diagnoses include Autism, Language disorders and Sensory impairment (Hyman, 2007).

The American Psychiatric Association (2018) notes that intellectual disability affects approximately one percent of the population. This is confirmed in a meta-analysis of international studies which found the prevalence of intellectual disability across the life span to be 1.04% (Maulik et al., 2011). However, data from this meta-analysis found the prevalence of intellectual disability in children and adolescents to be higher, at 1.83% (Maulik et al., 2011). People with intellectual disability have varying degrees of impairment which are typically classified as mild (IQ 69-52), moderate (IQ 51-36), severe (IQ 35-20), or profound (IQ 19 or below) (Sulks, 2019). The vast majority - 85 percent - of intellectual disability diagnoses are considered mild (American Psychiatric Association, 2018). Symptoms of moderate, severe, or profound intellectual disability, such as delays in language or motor skills, are typically observed by age two, however mild levels of intellectual disability are often not identified until a child reaches school age and begins to demonstrate difficulty with academics (American Psychiatric Association, 2018).

While there is no cure for intellectual disability, the overall goal of treatment is to reduce the effects of functional impairments and to help each person with intellectual disability reach his or her potential (Harris, 2006). A comprehensive and interdisciplinary approach that is tailored to an individual's specific needs is typically used to treat children and adults with intellectual disability and often includes the provision of positive environmental supports, educational interventions and skills development (Harris, 2006). Harris (2006) notes that "enormous progress has been made in providing educational services for children with intellectual disability and associated impairments and community programs and supportive employment for adults" (p. 6). He cautions, however, that behavioural and emotional problems in children and adults with intellectual disability often prevent their full participation in these programs (Harris, 2006).

Individual support needs for individuals with intellectual disability are often more closely associated with adaptive skills than standardized intelligence test scores. Consequently, a person with only a mild impairment on an intelligence test may require extensive support due to poor adaptive skills (Sulks, 2019). Sulks (2019) notes that support levels for individuals with intellectual disability typically fall into four main categories; (a) intermittent – occasional support needed; (b) limited – support such as a day program; (c) extensive – daily, ongoing support, and; (d) pervasive – high level of support for all activities of daily living.

Despite early intervention, poor adaptive skills cause many individuals with intellectual disability to struggle to manage their affairs effectively (Sandjojo, 2018; Sigafoos et al., 2005). These struggles can range from difficulties with personal and household care to trouble with community participation and employment (Ramdoss et al., 2012; Sandjojo, 2018; Smith et al. 2015). Consequently, many individuals with intellectual disability remain at least partially dependent on the support of family and care workers throughout their lifetime (Sandjojo, 2018; Vilaseca et al., 2017). Despite this, various studies of post-school outcomes of individuals with intellectual disabilities have found more favourable outcomes when educators, employers, community agencies and family members work together to establish viable transition plans (Hendricks & Wehman, 2009; Newman et al., 2011; Park & Bouck, 2018). As such, the following section will explore current literature pertaining to person centered transition planning and its current implementation in Ontario schools.

Person Centered Transition Planning

The transition from school to adulthood presents challenges for all adolescents. This transition can be especially difficult for students with special needs and often requires careful planning to enable each student to achieve the highest level of independence possible as adults. Traditional transition planning offered little choice for young people and their families, was marked by low levels of inclusion by relevant stakeholders and favoured outcomes that suited service providers rather than service users or caregivers (Haehne & Beyer, 2014). Due to poor transition outcomes under the old model, person centered IEP transition planning has come into favour in recent years. The move to person centered IEP transition planning is because transition plans have proven most effective when they are driven by the wants and needs of students and their families (Croke & Thompson, 2011; Hanger et al., 2014; Jackett, 2010; Wehman, 2001).

Person centered transition planning gained ground in the 1980s as a response to ideological developments that focused on the benefits of inclusion of people with disabilities (Robertson et al., 2006). Person centered plans place the student in the driver's seat as they require the active involvement of students and their families and friends in the transition planning process (Wehman et al., 2001). Person centered planning also improves the likelihood of post-school success (Croke & Thompson, 2011; Hanger et al., 2014; Jackett, 2010; Wehman, 2001).

Person centered transition planning rests on the meaningful involvement of exceptional students and their families in the planning of their own futures. Strong individualized, comprehensive and results oriented transition plans are most effectively created when students and parents actively participate throughout the entire transition planning process (Carnaby & Lewis, 2005; Hagner, 2014; Rehfeldt et al., 2012; Wehman et al., 2001). Further, a direct relationship exists between student and parent participation in the transition planning process and positive transition outcomes (Cameto et al., 2004; Griffen et al. 2014; Wehman, 2014). There are, however, barriers to achieving strong person centered transition plans.

Barriers to the creation of person centered transition plans.

While person centered transition planning is considered best practice, there are key challenges involved in the creation of person centered plans for individuals with intellectual disabilities. These challenges are due, in large part, to the fact that profound intellectual disabilities are marked by difficulties with social interaction and communication. These difficulties make it hard for some young adults with intellectual disabilities to actively participate in group activities such as transition planning meetings (Hagner et al., 2014). Additionally, individuals with intellectual disabilities often report increased levels of social anxiety and have vastly differing levels of adaptive behaviour, both of which may also serve as barriers to effective participation (Hagner et al., 2014).

Studies have shown how an individual's ability to participate and communicate can impact transition planning outcomes. Griffin et al. (2014) found that those students who attended transition planning meetings tended to be higher functioning in their communication and self-advocacy skills. Similarly, in their study of 15 exceptional students, Carnaby and Lewis (2005) found that students who were able to speak for themselves were more likely to be actively involved in their transition planning meetings. They noted that students requiring even moderate levels of communication support were more likely to be excluded from transition meetings or forced to sit through discussions that were irrelevant to their transition process. Kaehne and Beyer (2014) assert that accessibility is key if transition planning meetings are to place the needs and wishes of the young person at the center of the planning process as required by the person centered approach. After noting a lack of accessibility in transition planning meetings, Carnaby and Lewis (2005) achieved higher participation levels by using formats and materials that were more meaningful to the transitioning youth. Further, they also found that utilizing meeting styles that aligned with the abilities, interests and skills of the transitioning youth served to foster higher levels of participation.

Person centered transition planning affords young people and their families with more opportunities to articulate their own wants and needs. Thus, an increase in person centered transition planning has the potential to create new service demands. Given that these service demands may differ from the current services being offered, Kaehne and Beyer (2014) postulate that service agencies may struggle to meet these newly articulated service requests. Further complicating this issue is the fact that stakeholders from adult social service agencies tend to be absent from the transition planning team (Kaehne & Beyer, 2014). As such, person centered planning initiatives are not necessarily synonymous with an improved range of post-school service possibilities.

In their review of person centered transition planning, Claes et al. (2010) caution that this planning model is in danger of becoming a mere paper exercise if these plans are driven by service availability rather than service request. The authors note that planning around service availability alone fails to increase independence, choice or inclusion for transitioning youth. Planning around service request, however, is also problematic as even carefully crafted transition plans, built on the needs and desires of young people and their families, are little more than wasted effort if these young people later find themselves placed into available services that do not meet their original wants or needs (Clases et al., 2010; Kaenne & Beyer, 2014).

Person centered transition planning has the potential to improve the involvement of stakeholders in the transition process. Unfortunately, the long term measured impact of this involvement has been postulated rather than systematically reviewed. Wehman et al. (2014) suggests that increased research efforts are essential to demonstrate how the self-determination inherent in person centered transition planning influences the transition outcomes for young adults with intellectual disabilities.

While more research on the long-term impact of person centered transition planning is required, all of Canada’s provinces stress that transition planning should be incorporated into a student's individualized education plan (Towle, 2015). Additionally, every province has transition planning policies and/or documents (Towle, 2015). The following section will examine Ontario's transition planning practices in detail.

Person centered transition planning in Ontario.

Person centered transition planning is not a cure-all for tackling all the obstacles faced by exceptional students as they transition to adulthood. Nonetheless, the implementation of person centered transition models is seen as beneficial for students as it increases student participation in the planning process; identifies clear goals for support and intervention; provides group support; and results in more appropriate post-school destinations (Bakken & Obiakor, 2007; Kaehne & Beyer, 2014). Given this, it is apparent that the active involvement of young adults and their parents in the creation and ongoing evaluation of IEP transition plans is a crucial element to their success. This position aligns with that held by the Ministry of Ontario as it requires that school personnel work alongside students and their families in their efforts to prepare adequate transition plans for their exceptional students.

In Ontario, legislation requires that IEP transition plans be developed in consultation with a student's family and must include the student once he/she reaches the age of 16. Monitoring requirements for IEP's are laid out by the Ontario Ministry of Education. Under these requirements, principals must ensure that students and their families are involved in the transition planning process whenever possible (Ontario Ministry of Education, 2000). It can therefore be concluded that Ontario has made an effort to facilitate student centered transition planning as the province has guaranteed students and their families the right to take part in the planning process.

Aside from parents and students, the involvement of relevant community members, such as school personnel, district staff, and community representatives is a critical component of successful person centered transition planning (Johnson et al., 2002; Hagner et al., 2014; Rehfeldt et al., 2012; Westbrook et al., 2015). As experts in their own fields, these community members are able to help shape the development of a transition plan to best meet the expressed needs of students and their families. In Ontario, transition planning is seen as a collaborative activity and schools are required by the Ministry of Education to involve a team of people vested in supporting and assisting a student to achieve his or her goals. According to the Ministry, the transition planning team typically includes students who are aged 16 and over and their family members; one of the student's teachers and support personnel; and relevant representatives from organizations that will provide post-school support (Ontario Ministry of Education, 2002). Here again, Ontario can be seen to be embracing the principles of the person centered transition planning model given that provincial legislation requires the active involvement of relevant community members in the planning process.

Person centered transition planning places emphasis on the wants and needs of exceptional students in the planning of their own futures. Additionally, this model strives to include the individual's family and relevant community members in the planning process. In its transition planning policies, the Ontario Ministry of Education has enacted legislation which requires that these tenets of the person centered model be upheld. Given all this, it is apparent that IEP transition planning regulations in Ontario incorporate a person centered approach. However, with no published statistics regarding the outcomes of its transition plans, it is hard to ascertain the overall success of Ontario's model. On paper, Ontario's transition planning regulations appear to foster a person centered approach, but the degree to which individuals, their families, and community members are actually involved in the process remains unclear.

Additionally, in order to quantify the actual success of current transition planning, research that follows these students into their postsecondary lives is required.

This chapter will now change direction and turn to the closure of residential facilities, an initiative that moved Ontario away from an institutional care model and returned individuals with intellectual disabilities into the care of their families and communities.

Closing of Ontario's Institutions for People with Intellectual Disabilities

The Government of Ontario opened its first institution for people with intellectual disabilities in 1876. At the height of its operations, Ontario ran 16 such institutions and provided residential care to more than 10,000 individuals with intellectual disabilities (Ministry of Community and Social Services, 2018, para. 1). In 1974, the Government of Ontario passed The *Developmental Services Act* transferring the responsibility for services for people with intellectual disabilities from the Ministry of Health to the Ministry of Community and Social Services. According to the Government of Ontario, the ratification of this act "marked the beginning of the shift to a new way of providing services and supports to people with an intellectual disability, one which focused on greater independence, social inclusion and personal choice" (Ministry of Community and Social Services, 2018, para. 3). This Act was the impetus for moving Ontario away from an institutional care model.

While the move to close residential facilities was a key component of the revolutionary approach to disability policy that was happening at the time (McCauley & Matheson, 2016), it was also a potential tool for fiscal savings. An article from the Globe and Mail that was published in 1996 discussed the pending closures of three institutions located in Barrie, Palmerston and Picton (Globe and Mail, 1996). The article notes that the closure of these institutions would see one thousand individuals with intellectual disabilities moved into the surrounding communities and result in a savings of $60 million dollars (Globe and Mail, 1996). The following day, the Globe and Mail published a correction which indicated that the $60 million dollars was not savings but, rather, money that would be re-invested in community services for the affected residents (Globe and Mail, 1996). Although I conducted a thorough online search, details on how the $60 million dollars was reallocated and what percentage was spent on community services could not be found.

The Globe and Mail article quotes then Minister of Social Services, David Tsubouchi, as saying the closures would "provide disabled people [*sic*] with the opportunity of having a better quality of life" (Globe and Mail, 1996). Further, Nancy Stone, then president of the Ontario Association of Community Living was quoted as saying "we have all been working so long and so hard to see the day when people who are housed in institutions are welcomed back into the community with dignity" (Globe and Mail, 1996). While the closure of these institutions was well intentioned, the community supports and assistance implemented at this time did not facilitate a better quality of life or an increase in dignity for the vast majority of individuals with intellectual disabilities. In their 2016 review of the policy recommendations and legislation that shaped Ontario's transition from an institutional system to community living for individuals with intellectual disabilities, McCauley and Matheson note that most individuals with substantial developmental impairments were not able to afford the costs of comprehensive living supports and that disability pensions and employment supports did not allow those individuals who depend on them to live above a subsistence income. Further, they asserted that, while families should be able to look forward to their adult children with intellectual disabilities eventually transitioning from home into some type of community living, the required capacity for supported living did not exist in Ontario's communities. As detailed by the "Nowhere to Turn" report, Ontario continues to work to implement a sustainable alternative to the institutional care model more than 20 years after the closure of Ontario's institutions for individuals with intellectual disabilities.

Now that most individuals with intellectual disabilities are residing in their communities, this chapter will move to briefly discuss the supports currently available to young adults in Ontario once they have left their high school years behind.

Current Supports Available to Young Adults after Transitioning into Post-School Life in Ontario

In theory, Ontario currently offers significant support vehicles for young adults as they transition to post-school life. As individuals and families reach this milestone, however, the reality can be much different as they seek to replace the children's services that are no longer available to them with those that are offered to adults (L'Arche Canada, 2014). These lost supports include respite care, community supports, behaviour management programs, pediatricians, financial support and the programming and custodial care provided thorough the education system (Government of Ontario, 2018). Consequently, many advocacy organizations advise parents to plan early and to be aware that they may need to use their own financial resources to help and care for their adult children with intellectual disabilities (Families Matter Cooperative, 2014; Windsor-Essex, 2014).

The website of the Ontario Ministry of Children, Community and Social Services (MCCS) indicates that funding for services and supports for adults with intellectual disabilities is provided through the Passport Program. This program provides housing support in the form of group homes, specialized residences and the provision of monetary incentives to keep individuals with intellectual disabilities in the family home. Under the MCCS umbrella, financial support for individuals with intellectual disabilities is available through both Ontario Works (OW) and the Ontario Disability Support Program (ODSP) and support in finding employment is provided by OW (Ministry of Community and Social Services, 2018). While these various government supports are deemed available, accessing them can prove difficult and time consuming (CUPE, 2015; Dubé, 2016; L'Arche Canada, 2014; Spagnuolo, 2016; Windsor-Essex, 2014). Research exploring the benefits and limitations of Ontario's main support programs for adults with intellectual disabilities are reviewed in more detail below.

Potential federal government support.

Programs and assistance currently provided by Canada's federal government are explained in a pamphlet entitled *Services for People with Disabilities. Guide to Government of Canada Services for People with Disabilities and their Families*. These benefits focus mainly on federal tax credits, deductions and exemptions that reduce the income tax that a person with a disability is required to pay, as well as deductions for individuals or families that support a person with a disability. Additional supports include potential education grants for post-secondary students with a disability, subsidies to allow for home modifications, and a fund to help individuals with little or no work experience to prepare for and find paid employment (Government of Canada, 2006b). However, in Canada's governmental system, responsibility for provision of services to individuals with intellectual disabilities lies with the provincial government. Ontario's main support programs are identified and discussed below.

Ontario Works and Ontario Disability Support Program.

In their 2001 review of the Ontario Disability Support Program (ODSP) Kerr et al. note that the academic literature is critical of the Ontario Works (OW) program for offering limited services, being punitive in nature and requiring unreasonable follow up. They assert that the

ODSP appears to suffer from similar shortcomings and they point to insufficient benefits, increasingly restrictive eligibility criteria and a host of rules regulating individuals' lives. On its website, the Ministry of Children, Community and Social Services classifies ODSP as a program of last resort and advises individuals looking into ODSP to first explore financial viability through employment, the Workplace Safety and Insurance Board and the Canada Pension Plan Disability benefit (Ontario Ministry of Children, Community and Social Services, 2018).

Passport funding.

Passport funding allows people with disabilities to receive individualized funds that can be used to help them live as independently as possible. The funds are managed by the families and individuals themselves (Windsor-Essex, 2014). This self-management allows for independence and creativity in paying for personal support, skills development, recreational activities, etc. Demand for this program is high, wait lists are long, and advocacy agencies encourage parents of transitioning children to apply early, up to six months before their child's 18th birthday (Windsor-Essex, 2014). In his Ombudsman's Report, Dubé states that, while the Ontario government continues to increase funds allocated to the Passport program, the wait lists continue to grow exponentially. In 2012, 3,700 individuals were waiting for Passport funding. As of the end of 2015, that number had grown to 14,402 (Dubé, p. 22).

Housing.

Typically, youth with disabilities in Ontario face significant challenges in accessing housing and community and vocational services (Nguyen, Stewart & Gorter, 2017; Stewart et al, 2014). Ontario's housing system is facing a potentially insurmountable capacity crisis. In 2015, over 14,000 individuals with intellectual disabilities were on wait lists for appropriate housing (CUPE, 2015; Ministry of Community and Social Services Partnership Table, 2013) which are estimated to be 22 years long (Spagnuolo, 2016). Privately operated and publicly funded homes are allowed to set their own eligibility criteria for admitting residents and are also allowed to evict residents whose evolving needs and/or behaviours are deemed to fall outside of the admissions criteria (Spagnuolo, 2016). Spagnuolo (2016) contends that the impact of this evolving and arbitrary criteria for admission to housing is that “evaluation conducted by group home managers or other personnel determines access to fundamental supports” (para. 39). This position is also articulated by Paul Dubé in his 2016 Ombudsman’s Report which indicates that the ability of service agencies to provide and deny housing according to arbitrary selection criteria has led to a “service gap for a core group of individuals who are traditionally difficult to place” (Dubé, 2016, p. 120). So, essentially, the individuals and families most in need of supportive housing are the ones most often denied it.

In an overview of Ontario’s institutions and de-institutionalization produced by L’Arche Canada (2014) it is noted that some parents and supporters have successfully formed social advocacy organizations that have been able to obtain full or partial government support for community group homes and other type of supported housing. However, successes like these are few and far between, and the report goes on to note that Ontario faces a shortage of spaces in group homes, supported housing, day programs and employment opportunities for individuals with developmental disabilities. When there is no other viable alternative, it is often families who take on the responsibility of caring for their children with disabilities well into adulthood (L’Arche Canada, 2014).

In response to Canada’s housing crisis, which impacts a much wider population that just individuals with intellectual disabilities, a new national housing strategy was announced by the Liberals in November of 2017. In a *CBC* news article, Prime Minister Justin Trudeau is quoted as saying “housing rights are human rights, everyone deserves a safe and affordable place to call home” (*CBC*, 2017). A government backgrounder indicates that the “national housing strategy will help address a range of needs, from shelters and community housing, to affordable rental and home ownership” (Employment and Social Development Canada, 2017). Canada Mortgage and Housing Corporation (CMHC) states that the strategy is four pronged and will: (1) build new affordable housing by providing funding and financing opportunities; (2) renew and renovate existing affordable housing, again through the provision of funding and financing opportunities; (3) increase capacity and support within the community housing sector by providing technical assistance, tools and funding opportunities; and (4) encourage innovation and research into affordable housing and data (CMHC, 2019).

Dubbed “A Place to Call Home,” over the next decade the new housing strategy is anticipated to remove 530,000 families from housing need and cut chronic homelessness by 50% (Government of Canada, 2019). The mechanisms by which these ambitious targets will be achieved are laid out in a 2018 government publication entitled *Canada’s National Housing Strategy, A Place to Call Home*. A section of this document describes the proposed plans relative to Canada’s community housing sector. These plans include protecting 385,000 existing community housing units and building 50,000 more using $4.3 billion in federal funds, which the various provinces and territories are expected to match. Additionally, in order to protect tenants, $500 million will go towards developing new operating agreements as old ones expire (Government of Canada, 2018). While the intentions are laudable, exactly how, and how much, Canada’s new housing strategy will help individuals with intellectual disabilities and their families in the years to come remains unclear at this time. What is clear for now, however, is that many families continue to provide care in their homes for these individuals. The impact of providing this care is discussed in the next section of this chapter.

Development Services Ontario.

Development Services Ontario (DSO) manages the services provided to adults with developmental disabilities. On its website, DSO advertises itself as "your access point for adult developmental services" (Developmental Services Ontario, 2019a). The services DSO provides are funded by the Ministry of Children, Community and Social Services, and there are nine DSO locations across the province (Developmental Services Ontario, 2019a). These DSO offices emerged out of a 2004 governmental initiative aimed at transforming the adult developmental services sector. The nine DSOs were ultimately created in 2011"to provide a single-window point of access to adult developmental services throughout the province, using consistent criteria for eligibility and needs-based assessments" (Select Committee on Developmental Services, 2014, p. 6). Accessing developmental services through the DSO offices requires an application to determine eligibility. Further, the DSO website encourages youth to apply when they turn 16 in order to avoid service delays once they turn 18 (Developmental Services Ontario, 2019a) and transition from children's services to adult services.

The nine DSO offices across Ontario are determined by region. Each is administered by a different organization. For example, the DSO for the Hamilton-Niagara region is administered by Contact Hamilton, the DSO for the North Region is administered by Lutheran Community Care Centre, the DSO for the Toronto region is administered by Surrey Place while the DSO for the Eastern region, which includes the Ottawa location for this research is administered by Service Coordination (Select Committee on Developmental Services, 2014). To apply for services, an individual must go through his or her local area DSO. A search engine on the main

DSO website provides information on the address of the local DSO office but not the name of the administering organization (Developmental Services Ontario, 2019b). Once the name of the administering organization is known, however, it appears that each regional DSO office has its own website. An internet search shows that there is no uniformity across these nine websites but that each does contain relevant information needed to access developmental services for adults with developmental disabilities in Ontario.

As noted, the DSO offices were envisioned as a single point entry mechanism that would connect adults with developmental disabilities and their families with the services they require. These offices were established in 2011. Three years later, in 2014, the final report of the Select Committee on Developmental Services entitled *Inclusion and Opportunity: A New Path for Developmental Services in Ontario*, determined that the DSOs were not meeting this mandate and stated that agencies and individuals reported that "the establishment of DSOs has severed long-standing connections between families and local agencies, making it harder for families to navigate the system and for agencies to provide flexible solutions tailored to individual needs" (p. 6). The Select Committee for Developmental Services went on to recommend that the DSO mandate be revised with the intent to become more client-centred and to focus on individualized support and person-directed planning (Select Committee for Developmental Services, 2014).

The next topic to be discussed in this chapter is the impact that providing care to a loved one with an intellectual disability has on families and caregivers.

Caring for Adult Children with Intellectual Disabilities: A Family Affair

As noted in an earlier section, the 1974 ratification of the *Developmental Services Act* in Ontario began a 35-year transition away from an institutional care model which ended when Ontario closed the doors to its last remaining institution for individuals with intellectual disabilities in 2009 (Ministry of Community and Social Services, 2018). During this transition, many adults with intellectual disabilities left institutional care and returned to their communities, many of them back into the care of their families. Many of those individuals, as well as numerous others who have since entered adulthood, will continue to remain with their families at home for the foreseeable future.

Informal caregivers.

Relatives, partners, friends and neighbours who provide a broad range of assistance for an adult with a chronic or disabling condition are typically referred to as informal caregivers (Family Caregiver Alliance, Para 7). Informal caregivers generally provide care for personal rather than professional reasons and may care for individuals with a variety of conditions such as advanced age, prolonged illness and intellectual disability. While this care is typically provided out of love or a sense of family obligation, there is a considerable body of international research which suggests that informal caregivers endure great psychological, emotional and financial hardships (Bevans & Sternberg, 2012; Brodaty & Donkin, 2009; Eisner & Johnson, 2008; Gordon, 2009).

Statistics Canada reports that, in 2012, 8 million Canadians, roughly 30% of the population aged 15 and over, provided care to a loved one with a long-term health condition, disability or age- related problem (Turcotte, 2013). While informal caregivers typically provide care altruistically, the research reviewed in the following section indicates that the long-term experience of providing this type of care represents a chronic stressor. Thus, the term ‘caregiver burden’ is generally used to describe the psychological, emotional, social and financial toll of providing informal care (Bevans & Sternberg, 2012; Brodaty & Donkin, 2009; Eisner & Johnson, 2008; Gordon, 2009; Lawton 1991). While there are stressors associated with all types of informal caregiving, Statistics Canada data indicates that Canadians who provide care for their children with intellectual disabilities report the highest levels of psychological and financial difficulties resulting from their caregiving responsibilities (Turcotte, 2013).

Intellectual disability categorizes a range of developmental conditions which are characterized by lifelong deficits in cognitive function and adaptive skills (Genereaux et al., 2015). Children with intellectual disabilities require more doctors' appointments, medications, specialized equipment, and caregiver time than do their typically developing peers. The Statistics Canada data mentioned above, along with numerous other national and international research studies, demonstrate that the families of children with intellectual disabilities report significantly higher levels of stress and shoulder a larger economic burden than the parents of typically developing children (Cadman et al., 2012; Ganz, 2015; Van Tangerloo et all., 2015; Vogan, 2014; Zaidman-Zait et al, 2014; Zaidman-Zait et al, 2016). Further, due to the retention of significant impairments into adulthood, the level of care that most individuals with intellectual disabilities require does not diminish as they age (Vogan et al., 2014). As such, many continue to remain reliant on their families for support well into adulthood and beyond (Cadman et al., 2012; Robinson et al. 2016; Van Tangerloo et al., 2014; Vogan et al., 2014). This results in significant levels of caregiver burden for the families who continue to provide this needed support for their adult children with intellectual disabilities.

Caregiver burden.

The burden faced by those who provide care to a live-in family member was first acknowledged in a British study conducted by Grad and Sainbury (1963) in the early 1960's (Chou, Lin, & Lee, 2011). Grad and Sainbury interviewed nearly 400 informal caregivers to try to determine whether mentally ill patients should be treated inside or outside a hospital setting. They concluded that the health, attitudes and economic situations of families should be considered when deciding between inpatient and outpatient services and identified five symptoms that were associated with a ‘severe burden’ on families. These were aggression, delusions, hallucinations, confusion, and inability to self-care (Grad and Sainbury, p. 545).

The understanding of caregiver burden was later expanded by American researchers Zarit et al. (1980) to acknowledge the importance of subjectivity in the experience of burden (Chou, Lin, & Lee, 2011). Zarit et al. interviewed 29 family individuals who provided care for family members with age-related dementia. They associated caregiver burden with the negative consequences of providing care on the caregivers’ health, psychological well-being, financial situation and social life. However, Zarit et al. also found that caregivers reported less burden when they had access to adequate social supports. They concluded that the extent of the caregiver burden reported was associated more with the social supports available to the caregiver rather than the behavioural problems resulting from the dementia (Zarit et al., p. 653).

Building on the work of Zarit et al., American researchers Kosberg and Cairl (1986) developed a Cost of Care Index that was specifically designed as a “case management tool for assessing the potential and actual consequences of caring for an elderly person by informal care providers” (p. 275). They stressed that the attitudes and characteristics of a potential caregiver must be recognized and considered before placing an elderly person in their care (p. 274). They concluded that a tool, such as their Cost of Care Index, should be used to assess the appropriateness of family members as care providers for ill and dependent family members (p. 277).

At the same time, American researchers Montgomery et al. (1985) expanded the definition of caregiver burden to explicitly include both subjective and objective dimensions.

Montgomery et al. (1985) interviewed 80 informal caregivers who were providing care to elderly relatives and divided their reported burden into two categories, these being subjective burden and objective burden. They concluded that, while subjective and objective burden were correlated, they could be predicted by different factors. They found that subjective burden was related to the individual characteristics of the caregiver while objective burden was related to the type, amount, and duration of caregiving tasks performed. Given that subjective burden measures characteristics of the caregiver that cannot be easily altered, such as attitudes and feelings, Montgomery et al. concluded that intervention measures are not likely to ease this type of burden, however, they contended that interventions that free up some of the caregiver's time would serve to reduce their level of objective burden. Owing to the work of these researchers, the informal caregiving experience is today seen as an interactive event that occurs between a caregiver and a care receiver within a given social context (Chou, Lin, & Lee, 2011). Thus, the subjective burden of providing care is built on the feelings and attitudes of the caregiver while the objective burden rests on events and activities related to caregiving (Chou, Lin, & Lee, 2011).

Various researchers have identified factors associated with an increase in the caregiver burden faced by the informal caregivers of individuals with intellectual disabilities. These include additional behavioural concerns, aggression, severe disability, the presence of comorbid psychiatric disorders, and low levels of adaptive behaviour (Cadman et al., 2012; Ganz, 2015; Greenberg et al., 1993; Heller et al., 1997; Pinquart & Sorensen, 2006; Van Tangerloo et al., 2015; Vogan, 2014). Researchers have also identified a variety of factors which can help to alleviate the burden faced by informal caregivers including the provision of social supports and respite care.

Alleviating caregiver burden.

Zarit and collegues first acknowledged the importance of subjectivity in the experience of caregiver burden in the early 1980's. Since that time, scholars have linked the educational and income level of informal caregivers (Green, 2007; Manor-Binyamini 2011; McManus et al. 2011) along with their physical health (Chou et al. 2011; Magana et al. 2002), effective coping style (Robinson, 2016; Stuart & McGrew 2009), lower parental age and positive marital status (Al-Krenawi et al., 2011) with a decrease in subjective burden. Given that subjective burden is built on characteristics of the caregiver that cannot be easily altered, Montgomery et al. (1985) concluded that interventions were not likely to ease subjective burden. As an overall concept, however, helpful social supports are seen to have positive impacts on the subjective burden of families who provide informal care to children with intellectual disabilities. Greenlee et al. (2006) interviewed 106 informal caregivers of adults with intellectual disabilities and found a negative predictive relationship between caregiver burden and perceived social support (p. 3). Moreover, social supports have been correlated with lower level of stress (Dyson 1997; Feldman et al. 2002; Robinson, 2016; Smith et al. 2001), distress (Gallagher et al. 2008; Robinson, 2016) and marital problems (Dunn et al. 2001).

The term social support refers to various types of support, assistance and help that people receive from others. Social supports are generally categorized into three main categories: emotional, instrumental and informational support (University of California, para. 2). Emotional support is typically seen as the intangible things that people do that make us feel loved, appreciated and reinforce our sense of self-worth, while instrumental supports are various types of tangible assistance that others may provide, such as the provision of transportation, money and childcare. Informational supports can be tangible or intangible and represent the help that others may offer through the provision of information (University of California, para. 2). Thus, research indicates that the supply and availability of good quality emotional, instrumental and informational supports help to reduce the level of caregiver burden reported among the informal caregivers of adults with intellectual disabilities.

Montgomery et al. (1985) contend that interventions that free up some of the caregivers' time would serve to reduce their level of objective burden (p. 24). This finding continues to hold true today as the parents of children with intellectual disabilities continue to report vast demands on their time. As such, Johnson et al. (2005) note that respite care is "regarded by many parents as one of the most important supports necessary to continue to care for a child with special health care needs at home" (p. 509). Furthermore, in a comprehensive study of informal caregivers of children with intellectually disabilities, McManus et al. (2011) found that time obligations contributed more substantially to caregiver burden than did the financial obligations of care.

Respite care aims to alleviate the stress and burden associated with providing informal care to an individual with an intellectual disability. The parents of children with intellectual disabilities face immense care demands without the breaks or pay cheques afforded to formal caregivers (McManus et al., 2011; Perrin, 2002). Not surprisingly, informal caregivers of children with intellectual disabilities have reported experiencing a kind of 'double jeopardy' given that their caregiving duties impede their ability to fulfill their family, civic and societal roles (Green, 2007; McManus et al., 2011). These findings underscore the importance of respite programs that provide a 'temporary relief service' from the demands of unceasing caregiving (Southby 2017). In addition, research indicates that the break from caregiving that is facilitated by respite services can provide caregivers with a sense of renewal (Wilkie and Barr, 2008) and can encourage the development of independence and facilitate social opportunities for the recipients of care (Nankervis et al., 2011). Based on the foregoing discussion, it is evident that provision of respite care is an essential element in the alleviation of caregiver burden among the parents of adult children with intellectual disabilities.

The next section of this chapter will look at recent Canadian studies related to the transition of young adults with intellectual disabilities from school to post-school life.

Recent Empirical Studies on Transition in Canada

At the time that I began this research, there were very few empirical studies on the transition faced by young adults with intellectual disabilities and their families when they aged out of the public school system. Over the last seven years, this transition has witnessed an influx of attention from researchers and journalists. However, the bulk of the academic publications concerning this transition are based on the experiences of families in the United Kingdom and Australia. Consequently, a lack of available information concerning the overall transition to adulthood for young adults with intellectual disabilities persists in the Canadian literature. Only four such studies were located for this literature review. Their findings are discussed in detail below.

In 2014, Stewart et al. conducted a qualitative study exploring the “experiences of youth with different disabilities from across Canada during their transitions from adolescence to adulthood” (p. 1998). They conducted focus group interviews with 50 people, including youth with different disabilities, parents, caregivers and various service providers from across Canada. Their research identified an overarching theme of ‘complexities’ to the interactions between individuals with intellectual disabilities and their environment during the transition experience. The authors built their argument on the concept of person-environment fit, which assumes that a dynamic and interdependent relationship exists between persons and their environment and that there is a ‘good fit’ when there are societal supports in place to facilitate this relationship and a ‘bad fit’ when there are barriers hindering the relationship (Caplan, 1987; Stewart et al. 2014; Roberts & Robins, 2004). Stewart et al. contend that “daily life experiences, starting in childhood, influence the developmental journey of youth with disabilities: inclusive experiences promote a positive trajectory, but negative experiences and attitudes in the environment around youth can have a negative impact” (Stewart et al., 2003). Thus, they argue that the capacity of youth, family and community members must be built through useful and relevant information and the provision of appropriate services and supports. Finally, they postulate that “knowledge and application of these complex person–environment interactions during adult transitions for youth with all types of disabilities will increase through collaborative research and service planning among different service organizations and government departments” (Stewart et al., 2003).

In her 2016 dissertation, Hamdani conducted a qualitative study aimed at understanding the ways in which the transition to adulthood for young people with intellectual disabilities is problematized by policies and practices in Ontario. After completing a policy analysis and conducting in-depth interviews with 13 parents, she concluded that “normative assumptions about ways of being, becoming, and acting as an adult shaped an implied problem of disabled children [*sic*] and their inadequate progression to socially valued adult roles and activities” (Hamdani, 2016, p. iii). Further, she contends that these assumptions have both positive consequences, such as the promotion of feelings of self-worth and achievement, and unintended negative effects, such as social exclusion, stress and anxiety on young people with intellectual disabilities and their families. As such, she purports that policy makers have an opportunity to reshape disability policy in a way that mitigates unintended harmful consequences and improves the health and daily lives of young adults with intellectual disabilities and their family members.

In 2017, Gauthier-Boudreault et al. conducted a descriptive qualitative study aimed at better understanding the factors that help and impede the transition to adulthood for individuals with profound intellectual disabilities in Quebec. They interviewed 14 parents of young adults with profound intellectual disabilities and found that “the transition to adulthood is a critical period that is very stressful to parents of young adults with profound intellectual disabilities due to a lack of preparation to school ending and transfer to adult health services” (Gauthier-Boudreault et al., p. 25). In addition, they found that families were lacking material, informational, cognitive and emotional support at the time that their child transitioned from school. Thus, they concluded that transition planning in Quebec does not currently meet the needs of the families of adult children with profound intellectual disabilities and creates an emotional burden for caregivers.

Marshall et al. conducted research in 2018 with 8 parent/youth pairs in Western Canada in order to gain insight into “how young adults with intellectual and developmental disabilities and their parents jointly construct, articulate, and act on goals pertinent to the young adults' transition to adulthood” (p. 263). They identified three main categories that, when present, facilitated transition-based goals. These included emotional resources for parents, parental knowledge about intellectual or developmental disabilities and the ability of parents to advocate for their children. Further, they found that the absence of these resources hindered the attainment and creation of transition plans.

Overall, these studies conclude that successful transitions from school to post school life for young adults with intellectual disabilities require preparation, the availability of useful and relevant information and the provision of appropriate services and supports. Further, they all contend that additional research, collaboration between service organizations and governmental organizations, and policy change are imperative if Canada is to meet the needs of adults with intellectual disabilities as they transition out of high school.

The research on transition that I have undertaken in this thesis used Schlossberg's 4S model as its conceptual framework. The next, and final, section of this chapter provides an overview of this model.

Conceptual Framework – Schlossberg's 4 Ss Model

In order to help counsellors better assist adults through various types of life transitions, American psychologist Nancy Schlossberg developed a transition framework in the early 1980's. Her model presents a structural approach that is useful across various situations (Schlossberg, 2008; Anderson, Goodman, & Schlossberg, 2012). Schlossberg's framework incorporates the notion that adults are individuals with variable needs. She identifies three main types of transition. These include anticipated, unanticipated, and non-event transitions. Anticipated transitions involve the major life events which we expect to occur, such as graduating from high school, marrying, and having children. Conversely, unanticipated transitions occur unexpectedly and are often disruptive events such as major surgery, car accidents and job loss. Nonevent transitions are the expected events which fail to occur, such as not getting married or not being able to afford to retire (Schlossberg, 2011).

Schlossberg asserts that transitions do not have specific end points. Rather, she sees a transition as a process that takes place over time that include phases of adjustment and assessment as people move in, through and out of the transition (Anderson, Goodman & Schlossberg, 2012). Schlossberg contends that all transitions alter our lives and defines a transition as "any event, or non-event that results in changed relationships, routines, assumptions, and roles" (Anderson, Goodman, & Schlossberg, 2012, p. 39). For some, the process of moving from one set of roles, relationships, routines and assumptions to another is quick and easy. Others, however, are left floundering (Schlossberg, 2011). To account for this, Schlossberg identified four major sets of factors that influence a person's ability to cope with a transition, these being: situation, self, support, and strategies, which are also known as the 4 Ss (Figure1).

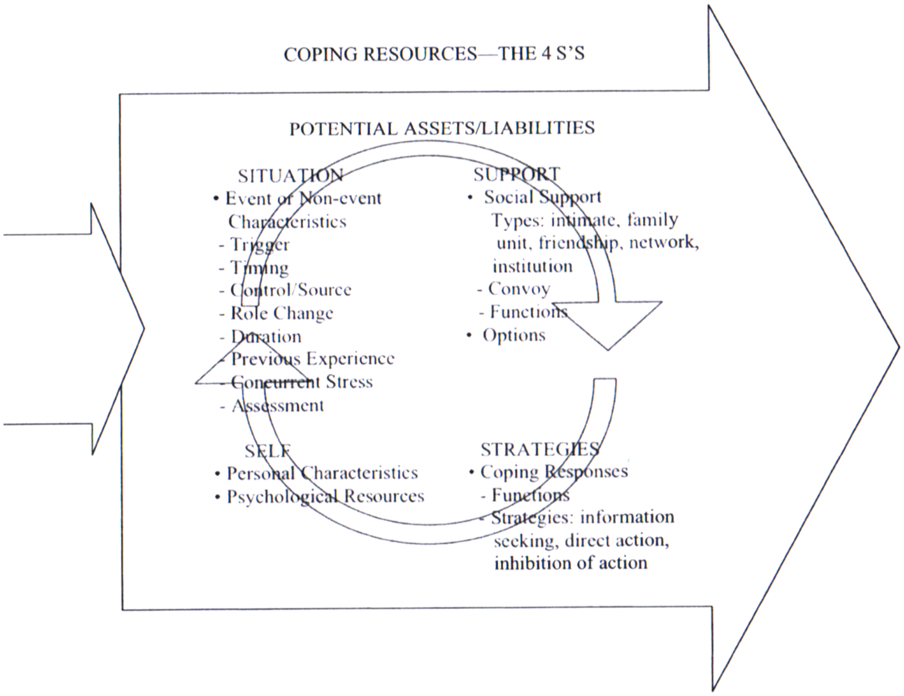

Figure 1 - *Schlossberg's Coping Resources; 4 Ss (Anderson, Goodman, & Schlossberg, 2012, p. 62).*

The Situation variable examines the features of a transition and how they may influence its significance to an individual (Evans, 2010). This includes such things as the transition's expected or unexpected nature, its level of desirability, its timing, the degree to which it can be controlled, and its level of permanency. The Self variable refers to an individual's inherent ability to cope with new situations. Schlossberg proposes that individuals who are optimistic and resilient have beneficial psychological resources at their disposal. Further, demographic characteristics such as socioeconomic status, gender, age and ethnicity also affect how individuals view and cope with challenges. The Support variable refers to the help available to the individual at the time of transition. Supports may include intimate relationships, family units, networks of friends or institutions and communities. Lastly, the Strategies variable refers to the ways in which an individual navigates transition. Strategic responses include those that modify a situation, control the meaning of a situation, and manage stress (Evans, 2010). While Schlossberg acknowledges that there is no single magical coping strategy, she notes that an individual's willingness to try many different coping strategies often results in a smoother transition (Schlossberg, 2008).

Schlossberg's 4 Ss model describes factors that make a difference in how one copes with transition. These four variables are viewed as either potential assets or liabilities during the transition process (Anderson, Goodman, & Schlossberg, 2012). The 4 Ss approach to transition helps to explain why different individuals react differently to the same types of transitions and why the same individual may have different reactions at different points in his/her life. When a person's transition assets outweigh their liabilities, adjustment is relatively easy, and when their liabilities outweigh their assets, adjusting becomes correspondingly more difficult (Anderson, Goodman, & Schlossberg, 2012).

Although it was originally intended to help counsellors better assist adults through periods of transition, Schlossberg's 4 Ss transition model provides a structure for analyzing many different types of transitions. Winter (2014), for example, applied Schlossberg's transition framework to study the multiple impacts that the transition into foster care has on children; Griffin (2015) used Schlossberg's transition theory to analyze qualitative data gathered from veterans and school personnel in order to determine how institutions could better support veterans' transitions to higher education; Harley, Beach and Alston (2008) used the 4 Ss model as a framework to investigate the effects of natural disasters on individuals with disabilities; Roncaglia (2010) used Schlossberg's model to investigate the experiences of career transition in ballet dancers; and Goodman and Anderson (2012) applied Schlossberg's transition model to their study on retirement. Additionally, Schlossberg's transition model has been used to analyze a variety of transitions in North American studies undertaken by Anderson and Goodman (2014), Goodman and Pappas (2000), Ryan et al (2011), Schaefer (2009) and Fishback, Pellegrino and Hoggan (2015).

In their discussion of transition theories, Evans et al. (2010) note that Schlossberg's transition theory is comprehensive in scope, integrative of other theoretical contributions and operationally sound. However, they are mindful of the fact that Schlossberg's theory has not been widely utilized by researchers. As such, they assert that it is difficult to affirm Schlossberg's transition theory until more studies are conducted using her theory. Further, Krumboltz (1985) reviewed Schlossberg's transition theory when it was first published in 1984 and concluded that, while it was a potentially useful instrument for analyzing transition, further examples of how it could be linked to practice were needed. Since this initial review, researchers using Schlossberg's transition theory have linked their findings to potential changes in practice across various fields. However, as highlighted by Evans et al. (2010), more studies are required.

Schlossberg's model has not, to date, been used to frame empirical work regarding the transition faced by the families of young adults with intellectual disabilities as their adult children transition from high school to their adult lives. My research will be the first to apply her 4 Ss model to this question. Researchers have successfully employed Schlossberg's transition theory in numerous different transition studies, and the framework fits well with the research presented here. Consequently, this research will use Schlossberg's transition theory as a tool to make sense of the transition faced by the families of young adults with intellectual disabilities when their children age out of high school. As previously noted, I elected to gather the transition stories of individuals with intellectual disabilities through the voices of their parents. Given this, the application of Schlossberg's 4 Ss model in this research is intended to shed light on the coping resources used by the parents of adult children with intellectual disabilities as their adult children age out of high school services. The application of the 4 Ss model is central to addressing my primary research question of how the families of adult children with intellectual disabilities understand and experience the transition that takes place when their children age out of high school.

Chapter Three: Methodology

Research Approach and Design

Researchers typically have a chosen worldview, or paradigm, which they use to inform and shape their studies. For the purposes of this research, I chose to ground my study in the principles of social constructivism. Social constructivism is rooted in a variety of academic disciplines and intellectual traditions. It is built on the integration of multiple theories and represents the coming together of behaviorist and cognitive ideals (Amineh & Davatgari, 2015). While social constructivism cannot be traced back to a single source, Shunk (2000) contends that its origins can be found in the developmental and social learning theories of Vygotsky, Bruner, Piaget, and Bandura. Further, Cresswell (2014) credits works such as Berger and Luekmann's (1967) *The Social Construction of Reality* and Lincoln and Guba's (1985) *Naturalistic Inquiry* with the advancement of the theory.

At its essence, "social constructivism is a theory of knowledge that examines the knowledge and understandings of the world that are developed jointly by individuals" (Amineh & Davatgari, 2015, p. 11). Social constructivism emphasizes the importance of culture and context in how we come to understand what occurs in society and, in turn, how we construct knowledge based on these understandings (Derry, 1999; Kim 2001). Reality, for social constructivists, is not something that can be discovered as it does not exist prior to its social invention (Kim, 2001). Social constructivists seek to understand the world in which we live. To do so, social constructivists rely heavily on research participants' interpretations of the phenomena which is being studied (Creswell, 2007). Social constructivism asserts that our interpretations are shaped by our interactions with others, and through historical and social norms. Social constructivism assumes that our understandings are socially constructed rather than innate (Creswell, 2007; Schwandt, 2007). Crotty (2009) describes constructionism as the view that “all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (p. 42). Accordingly, Crotty (2009) contends that meaning is not found but, rather, is constructed when humans engage with the world they are interpreting.

The understanding or meaning of phenomena, gleaned from participants and their subjective views, is the cornerstone of social constructivism because the understandings provided by participants are shaped by previous social interaction and personal histories (Creswell & Plano Clark, 2007; Schwandt, 2007). Research questions developed under a social constructivist model are typically designed to be broad and general in order to allow participants to construct meaning (Creswell, 2007). Thus, as this study is built on the premise of social constructivism, the primary research question that guided this study was purposefully designed to leave room for families to share their experiences and understandings of the transition that took place when their adult children with intellectual disabilities aged out of high school. Further, it is understood that the experiences and understandings shared by the participants in this study were shaped and constructed as these families interacted with the social and political realities of post high school life for their adult children with intellectual disabilities.

Creswell (2007) notes that social constructivism is typically manifested in phenomenological studies, where individuals describe their experiences, and in grounded theories, where theories are developed from the views and perspectives of individuals. After careful consideration as to the aim of this study, I chose to use a phenomenological approach for my research. I purposefully selected phenomenology as it strives to emphasize the meaning of an experience for a number of individuals and is a useful approach when one seeks to develop or improve policies surrounding a phenomenon (Creswell, 2007). Phenomenology is based on the work of philosopher Edmund Husserl and was further developed by his student Martin Heidegger (Corby, Taggart & Cousins, 2015; Flood, 2010). Van Manen (1997) defines phenomenology as “the study of lived experience” (p. 9). Corby, Taggart & Cousins (2015) further explain that phenomenological researchers attempt “to describe the participants’ experiences of a phenomenon and gain an insight into their world” (p. 452).

Social constructivism and phenomenology are typically associated with qualitative approaches (Creswell & Plano Clark, 2007). In general, qualitative data consists of open-ended information which is gathered through interviews with participants, written words, texts and images (Creswell & Plano Clark, 2007). Participants in qualitative research are afforded the opportunity to tell their story in their own words. Further, Flood (2010) notes that the interview is the main method of data collection in phenomenological research due, in large part, to the fact that interviews allow researchers to explore, illuminate and probe participants’ descriptions using reflecting, clarification, and listening techniques, and requesting further examples or explanations (Flood, 2010). Accordingly, the study presented here is built on qualitative data gleaned from semi-structured interviews with the families of adult children with intellectual disabilities who had recently aged out of high school in Ontario. It is complemented by data gathered from semi-structured interviews conducted with relevant community groups and government representatives. Further, a critical media analysis of the media’s coverage of, and portrayal of the needs of, adults with intellectual disabilities and their families rounds out this study. Figure 2 outlines the specific data sources which were used to address the four main research questions that frame this study.

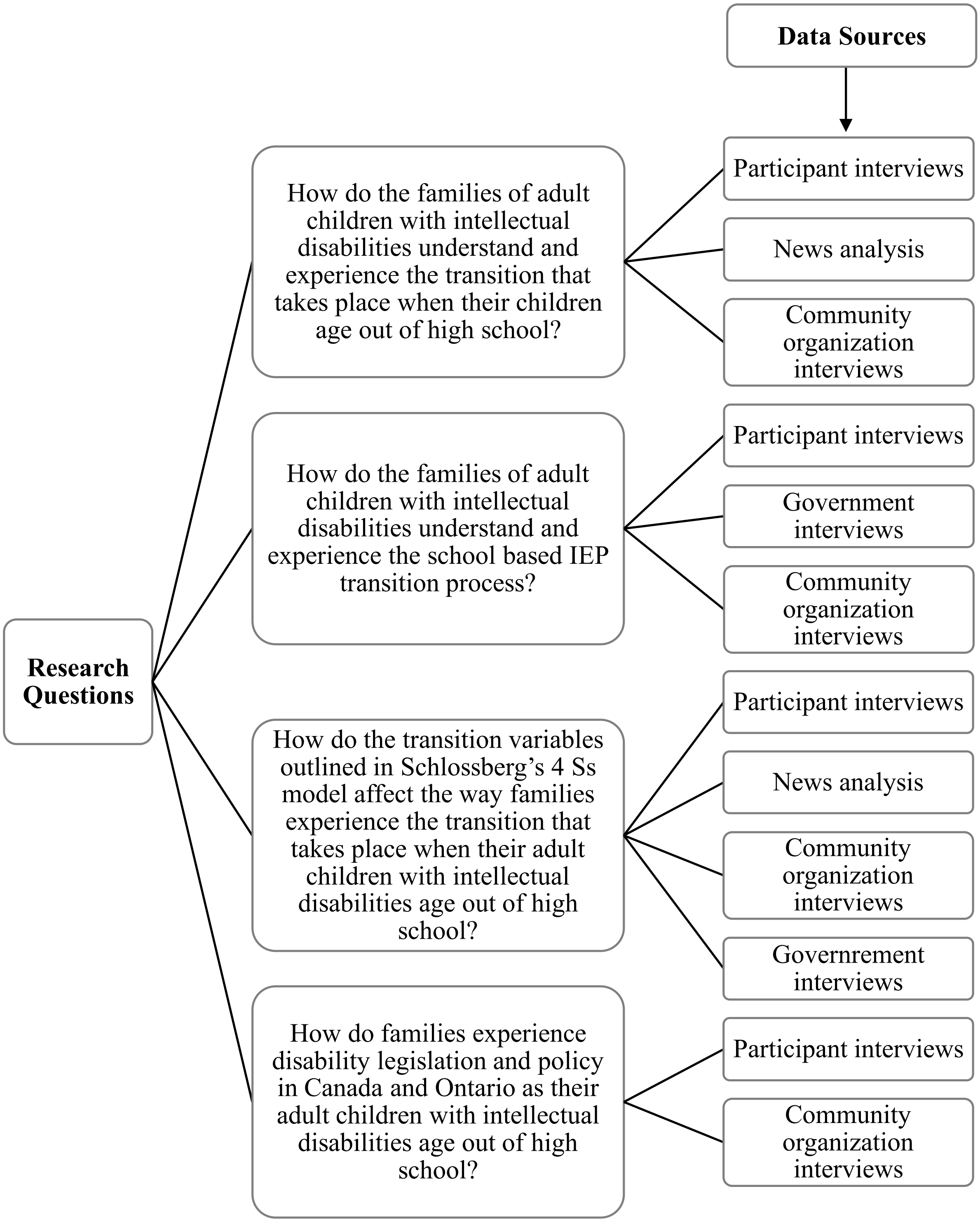

Figure 2 - *Research Questions and Data Sources*

Data Sources and Collection Strategies

The study presented here is multifaceted. As such, it is built on data gleaned from a variety of sources. These sources include the family members of adults with intellectual disabilities, relevant community groups, government policy and representatives and the news media. The following outlines how these data sources were identified and details the collection strategies that were employed in this research.

Families.

As previously noted, Ontario's transition planning regulations are intended to help exceptional students make a successful transition from school to work, further education, or community living (Ontario Ministry of Education, 2002). My research explores the phenomena of this transition as experienced by the families of adult children with intellectual disabilities. As such, I recruited the families of adult children with intellectual disabilities who had graduated, or aged out of high school in Ontario, within the last five years to participate in a semi-structured interview.

Mason (2010) notes that qualitative research is more concerned with meaning than making generalized hypotheses. As such, he contends that quantitative samples have a point of diminishing return as analyzing large samples can be quite time consuming, repetitive, and unnecessary. However, given that different participants may have diverse opinions, it is important that researchers ensure that their sample size is large enough to capture a wide range of these opinions. Mason (2010) asserts that researchers often use the concept of saturation as a guiding principle during their data collection. Saturation is deemed reached when the collection of new data does not provide any further insight into the issue being studied. However, Morse (1995) points out that researchers have a difficult time proving that saturation has been reached. Guest (2006) contends that 15 is the smallest acceptable sample size in qualitative research. Referring specifically to phenomenological research, Creswell (2007) notes that studies with 5 to 25 participants are appropriate, and Morse (1994) contends that at least 6 participants are necessary. Although these numbers have been offered as guidance to qualitative researchers, Mason (2010) points out that the authors do not present empirical arguments as to why these sample sizes are deemed appropriate. As Creswell's suggested sample size is specifically related to phenomenological research, I heeded his advice and interviewed five family members of adult children with intellectual disabilities who had recently finished high school for this study.

Before proceeding with either recruitment or interaction with participants or potential participants I submitted an ethics application on September 7, 2017, which was approved on November 7, 2017. I later modified my ethics application on September 27, 2018 in order to include interviews with community and government representatives in my research. This modification was subsequently approved on October 4, 2018. In accordance with ethics requirements, I submitted an annual report on October 9, 2018 and was granted a one-year continuance of my stated research.

I identified potential participants by posting recruitment posters at Ottawa organizations that work with young adults with intellectual disabilities (Appendix A). I originally intended to post flyers at a variety of organizations geared to supporting the families of, and individuals with, intellectual disabilities. However, only two of these organizations responded to my request. These organizations are the Y's Owl Maclure Co-Operative Center and the Families Matter Cooperative. The Y's Owl Maclure Co-Operative Center was founded in the early 1980's and works in partnership with the community to create daytime opportunities and employment for people with disabilities. At present, the Y's Owl Maclure Co-Operative Centre supports approximately 300 people across a range of services (Y's Owl Maclure, 2016). The Families Matter Cooperative offers support, information and networking opportunities for families who have loved ones with developmental disabilities. Although not as well rooted as the Y's Owl Maclure Co-Operative, the Families Matter Cooperative is well established in the community with over 10 years since its inception (Families Matter Cooperative, 2014).

As Y's Owl Maclure Co-Operative Centre and the Families Matter Cooperative are both cooperatives, they are built on the values of openness, respect and democratic control (Y's Owl Maclure, 2016; Families Matter Cooperative, 2014). Further, both these organizations are well established in the community and reach a breadth of families. As such, these locations were purposefully selected as potential recruitment sites for this research. Following my email request, both these organizations agreed to post physical copies of my recruitment poster on their bulletin boards as well as digital copies on their social media sites in February of 2018. After several months, three participants were recruited through these posters. Following meetings with these individuals, an additional two participants were recruited through snowball sampling, a non-probability sampling technique where existing participants identify other potential participants (Creswell, 2007). Once participants were identified, I conducted and recorded a series of open-ended interviews to gather the data necessary to complete this research. These interviews were conducted with the parents of adult children with intellectual disabilities who had recently transitioned from high school to the next phase of their lives. These interviews were held at a location convenient to the parents, typically a coffee shop, and lasted for approximately one to two hours.

Community groups.

Social networks are seen to provide the parents of children with intellectual disabilities with support and leverage to advocate and care for their children's needs (Munn-Joseph & Gavin-Evans, 2008). Accordingly, there are many organizations that strive to support families of children with intellectual disabilities by building their social networks. Two such organizations are Community Living Ontario and the Families Matter Cooperative. The Families Matter Cooperative helps families to provide a full and inclusive life for their loved ones with developmental disabilities in one municipality (Families Matter Cooperative, 2014). Community Living Ontario operates on a much larger scale as it "serves and advocates on behalf of more than 12,000 members across the province" (Community Living Ontario, 2018). As these organizations represent both a local and provincial perspective, they were chosen to inform and provide context to this research.

Given that social networks can be seen to represent a large portion of the 'support' component of Schlossberg's 4 Ss model, which I employed as part of this research, I reached out to these organizations in an effort to ascertain how they understand, experience and support the transition that happens when a family is faced with the termination of high school services for their adult children with intellectual disabilities. I contacted both Community Living Ontario and the Families Matter Cooperative via email and requested an interview. Despite numerous attempts, however, I only heard back from the Families Matter Cooperative. As such, I was only able to conduct a recorded semi-structured interview with a representative from this organization.

Government representatives.

Political will is commonly defined as the "demonstrated credible intent of political actors" (Malena, 2009, p. 15). Building on this definition, Brinkerhoff (2000) offers a more detailed description noting that political will is "the commitment of political leaders and bureaucrats to undertake actions to achieve a set of objectives and to sustain the costs of those actions over time" (p. 239). While both of these definitions appear straightforward, many authors contend that political will "entails many dimensions and reflects a large and multifaceted set of underlying factors" (Transparency International, 2014, p. 5). Consequently, it is important that political will not be reduced to a single, simple factor.

Brinkerhoff (2000) breaks political will down into four main driving factors. These are (a) individual factors, such as personal beliefs, aspirations and values; (b) organizational factors, such as mandates, culture and established practices; (c) relational factors, such as the participation of citizens and civil society; and (d) societal factors, such as the style of governance.

Ontario's Ministry of Education is the provincial government body responsible for educational policy, funding, curriculum and planning and direction in all levels of publicly funded education from kindergarten to grade 12. Appointed in 2018, Progressive Conservative MPP Lisa Thompson was Ontario's Minister of Education when I first sought to undertake interviews with governmental representatives. As such, Thompson sat at the helm of Ontario's special education programs and services and oversaw policies related to transition planning. Consequently, Thompson's political will had the ability to directly impact the transition planning that young adults with intellectual disabilities receive before aging out of Ontario schools. Given this, I requested an interview with Thompson to inform and provide context for this research related to government policies around the transition planning that happens in Ontario schools. MPP Lisa Thompson was unable to participate in this research, however an Education Officer with the Ministry of Education was directed to answer my questions.

Jim Munson is a Canadian Senator representing the Liberal Party of Canada. Following his career as a news reporter, Munson joined the Prime Minister's Office as a communications advisor in 2001. A year later he was made the Director of Communications and, a year after that, he was called to the Senate to represent the province of Ontario. Munson is a vocal advocate for individuals with autism spectrum disorder and is responsible for urging the Senate to adopt *An Act Respecting World Autism Awareness Day* and to undertake the Senate report *Pay Now or Pay Later: Autism Families in Crisis* (Parliament of Canada, 2018). Munson's political will to advocate for individuals with intellectual disabilities is, to some degree, driven by individual factors related to having a child with autism. As he is very outspoken on issues related to the health and wellbeing of individuals with intellectual disabilities and their families I requested an interview with him to inform and provide context to this research related to government policies and procedures around the support for the families of adults with intellectual disabilities during and after the transition that takes place when they age out of high school services.

Legislators do not work in silos. Consequently, "a central component of political will is the policy maker's assessment of whether or not he or she would be able to successfully implement the sought reform" (Transparency International, 2014, p. 6). Legislators need confidence in their abilities, the will of other important stakeholders, and the support of their government to implement desired reforms (Transparency International, 2014). Thus, a legislator's desire for policy reform often requires more than their individual will. The interviews conducted with Jim Munson and an Education Officer with the Ontario Ministry of Education are intended to inform this research rather than to measure political will related to disability policy. These interviews are intended to add information and provide context to the experiences described by the participants. My intent in interviewing these representatives was to ensure that a variety of perspectives and opinions were included in this research.

News analysis.

For the purposes of this study, news articles concerning the post-school lives of adults with intellectual disabilities were compiled from the Canadian Broadcasting Corporation (*CBC*) and the *Toronto Star*. The *CBC* is the only publicly funded national news broadcaster in Canada. The *CBC*'s 2016/17 Annual Report indicates that, in 2015/16, the *CBC*'s digital news site averaged 12.4 million unique visitors monthly, and their market share for *CBC* Radio One and Radio Two was 18.5% (*CBC* 2016/17 Annual Report). Unlike the *CBC*, The *Toronto Star* is privately owned by a subsidiary of a large media and publishing company called the Torstar Corporation. The *Toronto Star* is currently Canada's largest daily newspaper and boasts the largest readership in Canada, with 1.6 million daily on-line readers and 2.2 million print readers (Powell, 2016). Given the *CBC*'s national public broadcaster status, and the coverage and reach of the *Toronto Star*, these two news sources were purposefully chosen for this analysis as they were deemed to provide accounts of newsworthy issues in Ontario and across Canada. Furthermore, as Casciotti et al. (2014) note, news stories which originate in high readership sources are often picked up by smaller outlets and further disseminated to regional audiences. Thus, it is likely that the average Canadian news reader engages with the content published by one or both of these sources.

The news articles examined in this research were identified using a relevance, or purposive, sampling approach. Accordingly, articles from the *Toronto Star* and the *CBC* were retrieved by filtering ProQuest and the internal search tool available on the *CBC* to return results using the following terms: "development* disab* adult*". After further filtering these results to meet specific inclusion criteria, discussed in detail in Chapter 5, a total of 73 articles from the *Toronto Star* and 49 articles from the *CBC* were included in this research.

The amount of coverage that a specific issue receives in the media has the ability to influence public opinion about its importance. This perceived importance, in turn, has the potential to influence agenda-setting at the public and political level (McCombs & Shaw 1972; Weaver et al. 2004; Jacobson et al., 2012). Given this, policymakers, policy influencers and public opinions are all influenced by the media (Mao & Richter, 2014). Similar to the interviews I conducted with government and community organization representatives, the news analysis undertaken in this research is intended to shed light on issues deemed important by the media and to provide additional context to the application of Schlossberg's 4 Ss transition framework.

Plan of Data Analysis

Family interview data.

I recruited the families of adult children with intellectual disabilities who had recently graduated or aged out of high school in Ontario to participate in a semi-structured interview. The phenomenological data analysis which I utilized to understand these interviews is outlined below.

Defining bracketing.

As previously noted, phenomenology developed as a philosophical model under the tutelage of its credited founder, Edmund Husserl (Gearing, 2004). Husserl, originally trained as a mathematician, “set out to reestablish the science of philosophy by drawing from his training in mathematics to better understand the foundations of logic and generate a theory of knowledge” (Gearing, 2004, p. 1430). Husserl’s developing philosophy required researchers to directly investigate phenomena and to withhold any judgement that was not obtained from actively seeing or describing the phenomena in question (Gearing, 2004; Farber, 1967). Borrowing from his mathematics background, Husserl used the term bracketing to describe the suspension of judgment required in phenomenological studies. In mathematics, bracketing “suspends certain components by placing them outside the brackets, which then facilitates a focusing in on the phenomenon within the brackets” (Gearing, 2004, p. 1431). By employing bracketing techniques, Husserl alleges that phenomenological researchers are able to put aside their previous experiences, personal beliefs, and biases, thereby allowing them to better represent the experiences of their participants (Creswell, 2007; Corby, Taggart & Cousins, 2015; Flood 2010).

Creswell (2007) notes that researchers who embrace the concept of bracketing typically begin by describing their own experiences with the phenomena and then bracketing out their own views before proceeding with the experiences of their participants. However, as is the case with Creswell’s description, Gearing (2004) contends that qualitative researchers often provide vague and superficial descriptions of the bracketing process. Further, Mulhall et al. (1999) report that the literature around bracketing provides very little guidance which results in individual researchers creating and following their own conceptualization of the bracketing process. Kohak (1978) asserts that this shortcoming can be traced back to Husserl himself as he failed to put forth a clear, uniform definition of bracketing in his writing. Although phenomenological thinking has evolved over time, researchers continue to work towards a common definition and standard application of bracketing. Given this, Beech (1999) maintains that bracketing is a legitimate research tool only when researchers are “explicit about the process of bracketing so that others can observe and understand the rules of the game” (p. 44).

Tufford and Newman (2010) purport that the absence of a consistent definition and method of bracketing is both a challenge and a strength within qualitative research. They believe that the ambiguity around the practice of bracketing is encouraging researchers to grapple with, and locate themselves, along a continuum of practice. Simultaneously, bracketing can be used to support a variety of approaches. Chan et al. (2003) grappled with the ambiguity of bracketing in their own exploration of the lived experiences of Psychiatric Advanced Practice Nurses in Hong Kong. They put forth three concrete strategies to achieve successful bracketing. These include: (a) a strategy for mental preparation, (b) a strategy for planning data collection, and (c) a strategy for planning data analysis. After reviewing numerous articles which purported to outline the bracketing process, I determined that the strategies presented by Chan et al. (2003) were most clear and least difficult to follow. As such, I used these three strategies throughout this research.

Strategies to achieve bracketing.

Before undertaking original research, Chan et al. (2003) contend that the researcher should begin by confirming that they can put aside their own knowledge throughout their research. They contend that researchers should mentally prepare for their research by examining their consciousness and thoughts by asking themselves, for example, if they are humble enough to learn of others’ experiences and if they can adopt an attitude of conscious ignorance. If these questions can be affirmed, Chan et al. (2003) assert that the researcher can proceed with a phenomenological study. I asked these questions of myself and affirmed my ability to undertake a phenomenological study on the transition that families experience when their adult children with intellectual disabilities age out of the school system.

According to Gearing (2004) bracketing is best achieved if the literature review is delayed until after data collection and analysis. By delaying the literature review, research questions and data analysis will not be influenced from themes that arise in the literature (Chan et al., 2003; Streubert & Carpenter, 1999). However, Chan et al. (2003) point out that this is problematic for researchers given that gatekeeping bodies, such as ethics boards, funding organizations and thesis committees are likely to question the justification for the research if there is no linkage made between literature and the proposed research. As such, they offer a middle ground strategy for deciding the scope of the literature review whereby one stops the review process when they "understand the topic enough that [they] can justify the research proposal while maintaining [their] curiosity in this area" (p. 4). The thesis proposal and subsequent ethics application required for this research made it impossible to fully heed this recommendation. Consequently, I undertook an initial literature review at the onset of this study. Once I completed my data collection and analysis, I expanded this initial literature review to include the topics that were important to the parents I interviewed. My final literature review focuses heavily on the factors that influence the post-school life of young adults with disabilities as this was a strong focus of all my participant interviews.

Chan et al. (2003) provide a strategy for planning data collection to help phenomenological researchers prepare for face-to-face interviews. They note that in face-to-face interviews, the "directive of the questions and the manner in which the researchers ask them during the interview affects the way the participants tell their stories [which in turn limits] the potential new data given by the participants and affects the richness of the information collected" (p. 4). Thus, they contend that phenomenological researchers must be careful to ask focusing but not leading questions and listen carefully to participants. Accordingly, I developed an interview guide which consisted of a list of broad open-ended questions around the aims of this research (Appendix E). I was then able to ask questions for clarification or elaboration during the interview without limiting the participants' ability to introduce issues that I had not thought to ask about. Thus, as suggested by Ray (1994), the majority of the interview questions that I asked in this study were not predetermined and instead followed the cues of the participants (Ray, 1994).

Lastly, Chan et al. (2003) present a strategy for analyzing data derived from in-depth interviews. They note that researchers must further reflect on the aim of their study in order to choose between Husserl's descriptive approach and Heidegger's hermeneutic/interpretive approach to data analysis. One of the key differences between descriptive phenomenology and interpretive phenomenology lies in how these two approaches view autonomy. Husserl believes that humans are free agents who are solely responsible for influencing their environment and culture. As such, the impact of society, culture and politics on individual freedoms are not central to Husserl's descriptive approach (Cohen & Omery, 1994; Lopez & Willis, 2004). Conversely, Heidegger believes social, cultural and political contexts are deeply entwined in human experiences. Heidegger contends that an individual's freedom to make choices are restricted by the specific conditions of their daily lives (Lopez & Willis, 2004). Accordingly, interpretive phenomenology focuses on how participants' interactions with the world influence the choices they make. Additionally, an interpretive phenomenologist might also analyze the historical, social, and political forces that influence experiences (Lopez & Willis, 2004; Smith 1987).

This study aims to explore and understand the experience of the transition to post-school life as faced by the families of individuals with intellectual disabilities. This experience is couched in historical, social, and political forces related to individuals with disabilities. Therefore, after careful consideration, I concluded that interpretive phenomenology is the more appropriate approach for this research as it focuses on how individuals makes sense of a phenomenon within a given context (Chan et al., 2003; Lopez & Willis, 2004).

Amedeo Giorgi's five step method and Schlossberg's 4 Ss model.

Phenomenological researchers typically analyze data by looking for themes, patterns and trends. To further enhance their analysis, Corby, Taggart and Cousins (2015) note that researchers often employ particular frameworks or models of investigation. One such model is Amedeo Giorgi's five step method. Following these steps, researchers: (a) assume a phenomenological attitude; (b) read entire written accounts for a sense of their whole; (c) identify 'meaning units' which highlight the participant's experiences in relation to the phenomenon being studied; (d) probe each meaning unit for their essential meaning and, when finished, restate these units in academic language; and (e) develop a cohesive description of the essence of the phenomena based on the transformed meaning units (Corby, Taggart & Cousins, 2015; Devenish, 2012; Flood 2010; Giorgi, 2009). Throughout this process, it is expected that researchers engage in bracketing to avoid making judgements or relying on preconceived ideas.

Giorgi is a proponent of descriptive phenomenology. His method was therefore purposefully designed for descriptive studies. As this study approaches phenomenology from an interpretative lens, I adapted Giorgi's model to fit the needs of this analysis by including meaning units relative to historical, social, and political forces in my analysis. Employing this slightly adapted version of Giorgi's model, I used transcripts of the interviews that I conducted to write a composite description that presents the essence of the experience of the transition to post-school life as faced by the families of individuals with intellectual disabilities. I next applied

Schlossberg's 4 Ss model to Giorgi's meaning units to examine how the factors of situation, self, support and strategies influenced family experiences relative to the transition to post-school life for their adult children with intellectual disabilities. Schlossberg asserts that all transitions alter our lives. She defines a transition as "any event, or non-event that results in changed relationships, routines, assumptions, and roles" (Anderson, Goodman, & Schlossberg, 2012, p. 39). For some, the process of moving from one set of roles, relationships, routines and assumptions to another can be relatively easy. However, others are left floundering (Schlossberg, 2011). To account for this, Schlossberg identified four major sets of factors that influence an individual's ability to cope with a transition: situation, self, support, and strategies, which are known as the 4 Ss.

Government interview data.

Interviews with Senator Jim Munson and MPP Lisa Thompson were intended to inform this research. While Lisa Thompson declined to be interviewed, an Education Officer from the Ontario Ministry of Education, did participate in a telephone interview and follow up email correspondence. These interviews were intentionally conducted after family interview data was collected and analyzed so they did not influence the bracketing process. Additionally, these two interviews are not intended to stand alone but, rather, to provide context to the interpretative phenomenological aspect of this study. Therefore, the outcomes of the government interviews are reported on, but not phenomenologically analyzed.

Community advocacy organization interview data.

As with the government interviews detailed above, my interview with Ms. Marge McCabe of the Families Matter Cooperative, was conducted after family interview data was collected and analyzed. Again, this interview is intended to provide context to the interpretative phenomenological aspect of this study and, therefore, the outcome is reported on but not phenomenologically analyzed.

News analysis data.

Media content analysis helps to answer questions about how social issues are communicated through the media, shines a light on what the media deems newsworthy, and highlights topics that can potentially influence policy makers (Mao & Richter, 2014). Krippendorff (2004) defines content analysis as a research technique that makes replicable and valid inferences from data derived from text (Krippendorff, 2004). Further, Krippendorff (2004) contends that content analysts have a greater chance of drawing on and contributing to existing knowledge if they employ conceptualizations that have already been proven successful. To achieve this aim, he advocates that content analysts build on the instructions of published content analysis with similar aims. Given this, I have adapted the coding procedure used by Glenn, Champion, and Spence (2012) in their study of the news media coverage of weight loss surgery in Canada.

Glenn et al. (2012) applied four guiding questions to their content analysis, these included:

> (a) what is the primary/dominant intent of the message?;
>
> (b) who is speaking?;
>
> (c) who is the target audience?; and
>
> (d) what is the tone of the article? (p. 127).

As suggested by Glenn et al. (2012), all of the identified articles were read prior to commencement of analysis in order to promote immersion into the topic and to insure the appropriateness of the guiding questions. Given that these guiding questions address the same themes that are important to my research, this model was deemed a good fit and was adapted to meet the needs of this study. As it was difficult to consistently determine the target audience of each article, the target audience category was modified to examine the style of the article instead. Using the literary definition of writing style, news articles were coded as being either expository, persuasive, or narrative. The descriptive writing category was omitted as this style is more commonly found in fictional pieces.

Limitations

One of the difficulties associated with phenomenology is that the researcher is assigning meaning to relationships that are constantly evolving (McPhail, 1995). Phenomenological research also requires the researcher to respect the meaning making structures of their research participants and not impose their own beliefs or opinions (McPhail, 1995). It can be difficult to detect or prevent researcher bias and the literature can be vague on exactly how to accomplish this (Converse, 2012). There is no one who has better knowledge of the family experience of the transition that takes place when adult children with intellectual disabilities age out of high school than the participants themselves. All the reliability measures adopted by this research, including bracketing, aim to ensure that the findings of this study are representative of the participants' lived experiences and perceptions. As I undertook this research, I employed the strategies to achieve bracketing proposed by Chan et al. (2003) to ensure I remained neutral and impartial in this phenomenological research. Chan et al. (2003) note that "it is up to the researcher to commit to the issue of bracketing and to decide how much influence there can be by the researcher throughout the research process" (p. 7). I believe that I fully committed to the bracketing procedure thereby minimizing my influence on the results of this research.

I recruited participants by posting physical and digital copies of my recruitment poster at two organizations that provide services and support to individuals with intellectual disabilities and their families. Once I was contacted by a family member, I employed snowball sampling which allowed participants to identify other potential participants in their social networks. Given this, it can be concluded that all of my participants share at least one social network. Consequently, they are potentially more resourced or connected than a typical parent of an adult child with an intellectual disability.

Chapter Conclusion

This chapter presented an overview of the methodology that I used to shape and conduct this study. It presented all aspects from design and data collection to analysis and verification strategies. The next chapter will provide a history and overview of disability policy in Canada, an understanding of which is necessary before proceeding to the presentation and analysis of the various components of my research.

Chapter Four: Disability Policy in Canada

In 1977, The Canadian Council on Social Development looked to identify the state of Canadian services and programs for those suffering from a disability. The resulting study, undertaken by Joan C. Brown, was entitled *A Hit-and-Miss Affair: Policies for Disabled People in Canada.* Brown's study identified numerous shortcomings in Canada's delivery of services for the disabled including service gaps, delayed referrals, inadequate follow-up programs and a lack of linkages between the various social programs. In concluding her study, Brown identified two interesting themes. The first of these themes was what she called "a lively awareness of the many deficiencies in policies for disabled people in Canada together with a desire for constructive change (Brown, 1977, p.468). The second theme identified by Brown was a "strong sense of frustration that the need to change is not being recognized or is not being given an adequate priority at the level where decisions must be made" (Brown, 1977, p.468). Twenty-seven years later, in 2004, Michael J. Prince authored the article, *Canadian disability policy: still a hit-and-miss affair*, in which he contends that Brown's assessment remained a "fair portrayal of Canadian disability programs and services, especially so from the perspective of groups of, and for persons with disabilities" (Prince, 2004).

More than a quarter century passed between Brown's assessment of Canadian disability policy as a hit-and-miss affair in 1977 and Prince's assertion that the description was still very applicable in 2004. Given that 15 years have elapsed since Prince's article, the following sections of this chapter will explore the continued relevancy of three main themes highlighted in Brown's (1977) and Prince's (2004) reviews of Canadian disability policy. Accordingly, this chapter will review the current state of Canada's disability policy framework, national strategy and funding allocation.

Canada’s Disability Policy Framework

The Canadian Disability Policy Alliance is a self-described “national collaboration of disability researchers, community disability organizations and federal and provincial policy-makers, aimed at creating and mobilizing knowledge to enhance disability policy in Canada” (A Review of Disability Policy in Canada, 2017, p. 4). This organization has produced three intensive reviews of disability policy in Canada, the first edition in 2008, the second in 2013 and the current third edition in December of 2017. In the second edition, Bond and McColl (2013) analyzed Canadian disability policy and they noted that people with disabilities perceive disability policy in Canada as extremely complex and difficult to navigate, and that the lack of a coherent underlying ideology or policy framework is particularly concerning (Bond and McColl, 2013). In the 2017 edition, Mary Ann McColl et al. continued this theme, noting that Canadian disability policy is “a patchwork of legislation, regulations, programs, providers and entitlements that requires considerable probing to reveal, and considerable patience to understand” (McColl et al., 2017, p. 7 citing Boyce et al, 2001, Prince, 2004, Cameron and Valentine, 2001). They go on to further note that disability policy in Canada has been described by various researchers “as conflicting, fragmented, incoherent, not user-friendly, a ‘hit-and-miss’ affair” (p. 7).

In a 2016 article about disability and human rights, Theresia Degener notes that many different models of disability have appeared in the academic literature since the 1960s. These include the medical model, the social model, the economic model, the minority group model, and the universalist model, along with several others. She further asserts that the medical and social models of disability have been the primary models considered in the English-speaking world. Both these models were developed by disability studies scholars in the 1970s and 1980s and remain the most dominant models when describing disability (Degener, 2016). The medical model of disability asserts that all limitations associated with having a disability are the direct result of the disability (Blustein 2012; Haegele & Hodge, 2016; Humpage, 2007). Essentially, the medical model of disability regards disability as “an impairment that needs to be treated, cured, fixed or at least rehabilitated” (Degener, 2016). The medical model views the difficulties faced by people with disabilities as being independent of wider sociocultural, physical, or political circumstances. Consequently, any changes made to the environmental, physical, or organizational structure of society are seen by medical model theorists as insufficient to provide a disabled person with the same opportunities as a non-disabled person.

In contrast, the social model of disability contends that the challenges faced by people with disabilities are not due to their specific limitations but, rather, society’s failure to provide appropriate services that meet their specific needs. This theory is not without criticism. Dewsbury et al. contend that the social model simply replaces the biomedical discourse with a sociological discourse and that it still doesn’t recognize the actual and practical needs of the disabled, needs such as housing, employment and basic human rights (Dewsbury et al, 2004). In the conclusion to their 2006 book about disability and social policy in Canada, editors McColl and Jongbloed point out that other critics of the social model take issue with the fact that it fails to recognize the biological reality of disability. Criticism aside, the social model of disability is often viewed as the most appropriate model within which to frame disability. Proponents of this theory contend that public policy should focus on a commitment to eliminating barriers and providing accommodations rather than fixing people living with a disability (Haegele & Hodge, 2016; Humpage, 2007; Maholtra, 2012; Oliver 1999).

In recent years, the social model of disability has been complimented by a new model of disability, that being the human rights model. Degener asserts that the human rights model elevates the social model by recognizing six additional factors, as follows: (1) the social model explains disability as a social construct while the human rights model further acknowledges that human rights do not require a specific health or body status; (2) the human rights model adds to the social model's expectation of anti-discrimination rights by also including civil, political, economic, social and cultural rights; (3) the human rights model acknowledges that impairment is a condition of humanity; (4) the human rights model recognizes various layers of identity (for example, gender, race, sexual orientation, etc.) and acknowledges that intersectional discrimination can exist; (5) the human rights model accepts that impairment prevention policy can be sensitive to human rights; and, (6) the human rights model provides a roadmap for change (Degener, 2016). Pooran and Wilkie (2005) describe the evolution of concepts of disability from the medical model through to the social model which, in turn, spawned a rights movement "that sought valuation of people based on their inherent self-worth" (p. 3). They note that this shift in thinking refocused attention from the needs of people with disabilities onto their rights and recognized them as rights-bearing individuals (Pooran and Wilkie, 2005).

In his critique of Canadian disability policy, which spanned the years between 1981 and 2001, Prince (2004) asserts that the views and goals relative to disability held by the Canadian government contrast with those held by people with disabilities. Traditionally, disability has been understood according to the medical model of disability and, while official Canadian government documents do espouse the values of equality, inclusion and citizenship, Prince contends that the Canadian governments, both federal and provincial, continue to frame disability mostly within a bio-medical paradigm (Prince, 2004). From a conventional governmental perspective, disability policy making is about developing programs and services to meet the personal well-being and family security of people with disabilities (Prince, 2004). This focus on personal well-being and family security is evident when reviewing the Canadian government's current approach to providing disability support. Programs and assistance currently provided by Canada's federal government are laid out and explained in a pamphlet entitled *"Services for People with Disabilities. Guide to Government of Canada Services for People with Disabilities and their Families."* These benefits focus mainly on federal tax credits, deductions and exemptions that reduce the income tax that a person with a disability is required to pay, as well as deductions for individuals or families that support a person with a disability. Additional supports include potential education grants for post-secondary students with a disability, subsidies to allow for home modification, and a fund to help individuals with little or no work experience to prepare for and find paid employment (Government of Canada, Services for People with Disabilities, n.d.).

The personal well-being and family security approach taken by the Canadian government may not reflect the views of some individuals with disabilities who prefer the approach espoused in the social and human rights models of disability. When evaluated from a social model perspective, policy analysis looks at the abilities and aspirations of people with disabilities and assesses how well the programs and services are meeting these abilities and aspirations. Rather than evaluating policies through a social model of disability lens, the Canadian government continues to approach disability as a "category or set of categories of discrete needs" (Prince, 2004), and current disability policy analysis describes and explains the intentions, instruments and processes associated with the programs and services designed to meet these needs (Prince, 2004). As noted above, official government documents do work to promote the values of diversity, equality and inclusion, however, Canadian disability policies continue to be framed around the recipients' basic personal and financial needs rather than the recipients' abilities, aspirations and potential. In other words, as previously noted, disability is framed by the Canadian governments mostly from the perspective of the medical model of disability.

In her 2003 article about disability policy in Canada, Jongbloed contends that, as the various models of disability and disability policy have changed and evolved over time, they have also layered upon one another, with policies developed under the various models still existing decades later and not aligning well with current Canadian societal expectations. Jongbloed notes that there are no clear linkages between the various models of disability policy and their differing conceptual bases which makes it impossible to guide disability policy with any existing model. She contends that "decision making about the goals of disability policy and the rights of people with disabilities requires the development of a normative foundation" (p. 203). This assertion from Jongbloed's 2003 article aligns with recommendations made years earlier, in 1996, by a Federal Task Force on Disability Issues in their publication, *Equal Citizenship for Canadians with Disabilities, The Will to Act*. Recommendations from this report included the adoption of a disability policy framework to help the federal government to "achieve the objective of an inclusive society" (p. 25), as well as the development of a "disability lens" that would allow the federal government to "assess the impact of policies and programs" (p. 31).

Jongbloed (2003) asserts that consistent policy objectives would result from "the development of a normative foundation for analyzing the goals of respect, participation, and accommodation" (p. 208). In reaching this conclusion, Jongbloed states that the question of whether the main emphasis of disability policy should be on rights or on benefits needs to be addressed. She posits that doing so requires "an acknowledgement of the multidimensional nature of disability and an attempt to address the normative question regarding what society owes people with disabilities" (p. 208). Jongbloed's opinion that the establishment of a normative foundation requires deciding whether disability policy should be based more on rights or more on benefits underscores why Canadian governments and their citizens continue to grapple with disability policy. Rights and benefits are both critically important to people with disabilities and finding the appropriate policy balance between the two is a goal Canada appears to strive towards. However, in this regard, progress is slow as the on-going assessment of Canada's disability policy as a "hit-and-miss affair" (Brown, 1977, Prince, 2004) clearly indicates. That said, as models of disability continue to change and evolve, and as Canadian governments, Canada's citizens and various advocacy groups struggle to reach agreement on what disability policy should look like, what it should achieve and how it should be evaluated, the work required to develop a normative foundation continues to appear quite overwhelming. Consequently, the ongoing discourse and continual reframing of disability in Canada may have inhibited the development of a normative foundation, framework or lens upon which disability policy can be designed and evaluated.

The following section will discuss Canada's national disability strategy. Before doing so, it is important to define the differences and linkages between a normative foundation or framework and a strategy. Hanke and Stark (2009) clearly outline this difference stating that a conceptual framework, once developed, is then used to develop a strategy. While this chapter examines the foundation of Canada's disability policy and its national strategy as two separate issues, it should be recognized that there are potential links between the two.

Canada's National Disability Strategy

One of the stated goals of Canada's federal government is to increase opportunities and reduce barriers for people with disabilities, thus ensuring their ability to fully participate in Canadian society (Government of Canada, Rights of People with Disabilities, 2018). There are two main federal laws designed to protect Canadians with disabilities. The Canadian Charter of Rights and Freedoms prohibits discrimination of any kind while the Canadian Human Rights Act ensures all people, regardless of ability, receive equal treatment before and under Canada's laws (Council of Canadians with Disabilities, 2013). Additionally, as discussed in the preceding section, federal programs that provide financial assistance and subsidies do exist. However, the bulk of the actual provision of services to individuals with disabilities falls mainly to the individual provinces and territories. Provincial responsibility for disability services, supports and policy has created differences and inequities across the various regions of Canada (Burns & Gordon, 2010; Bond & McColl, 2013; McColl et al, 2017). These differences and inequities have long been recognized. Back in 1996, under the Liberal government, four members of the parliament of the time, Andy Scott, Andy Mitchell, Clifford Lincoln and Anna Terrana comprised the Federal Task Force on Disability Issues that authored the report *Equal Citizenship for Canadians with Disabilities, the Will to Act.* This task force consulted with many individuals from across Canada and reviewed briefs and submissions from more than 200 individuals and organizations (Scott et al., 199). They recognized the various inequities in disability policy across Canada and, in their report, they stated that "Canadians have the right to expect inclusiveness, equality and the opportunity to achieve equal outcome, no matter where they live" (p. 12).

In an undated article that can be found on the Abilities Canada website, Andy Scott wrote about his experiences as Chair of the 1996 Federal Task Force on Disability Issues. In this article, he acknowledged that his group was certainly not the first to have studied the issue of disability in Canada and he went on to note that "part of the reason the task force was created was because there had been insufficient action following those earlier recommendations" (Scott, 2016). That was in 1996; twenty-two years later, there is still insufficient action to remedy the differences and inequities in disability services across Canada's provinces and territories. Burns et al. (2010) asserts that inequity and discrimination still exist for Canada's disabled population. This assertion has also been strongly highlighted by The Canadian Disability Policy Alliance in their various editions of *A Review of Disability Policy in Canada.* Overall, as stated by Burns and Gordon (2010), a prominent theme exists in the Canadian literature that calls for federal disability legislation that is stronger, more cohesive across the country, and more effective than the existing Canadian Human Rights Act and Canadian Charter of Rights. New robust legislation is required to ensure that all provinces in Canada have appropriate services and programs available to protect and support persons with disabilities (Burns and Gordon, 2010).

Since the early 1980s, there has been governmental recognition of the need for a national strategy to address and unify the differing practices and services offered to the disabled across Canada's various provinces and territories. The first report to do so was released in 1981, The International Year of Disabled Persons. The report was authored by a Special Parliamentary Committee on the Disabled and the Handicapped, and was released by the federal Liberal government of the time. Entitled *Obstacles,* this initial report put forward 130 recommendations on various aspects of public policy related to improving the lives of persons with disabilities (Burns and Gordon, 2009; Disability and Information Research Alliance, 2006). Numerous other reports followed and several of these were released by the Federal, Provincial, and Territorial Ministers Responsible for Social Services. Federal, provincial and territorial ministers typically meet to discuss sectoral issues (Government of Canada, 2006b), and the various intergovernmental ministers accountable for social services spent a significant amount of time in the late 1990s and early 2000s focused on the development of a national strategy for

Canada's disabled. They produced several documents that advocated for a national strategy for persons with disabilities. These documents include: *In Unison: A Canadian Approach to Disability Issues* (1998), *Future Directions* (1999), *In Unison 2000: Persons with Disabilities in Canada* (2000) and *Advancing the Inclusion of Persons With Disabilities* (2002). All these reports included potential tactics for integrating services across Canada (Burns and Gordon, 2009).

For whatever reason, the Federal, Provincial and Territorial Ministers Responsible for Social Services stopped advocating for a national strategy for the disabled, and their string of publications on this topic ceased. In fact, when this group of intergovernmental ministers met in Edmonton in February of 2016, it was their first meeting in ten years (NL Department of Seniors, Wellness and Social Services, 2016), and priorities had shifted to other issues. In a governmental press release it was noted that the social issues discussed at the February, 2016 meeting included "reducing poverty, supporting high quality early learning and child care services, improving outcomes for Indigenous children and youth and removing and preventing barriers for people with disabilities" (Employment and Social Development Canada News Release, February 5, 2016). While this first meeting in ten years did include discussions relative to the disabled, these discussions focused on accessibility rather than on a national strategy. Further, when the group reconvened one year later in February of 2017, the focus on poverty reduction continued, as did the focus on accessibility for the disabled. Discussions relative to a national strategy for the disabled were not included (Employment and Social Development Canada News Release, February 3, 2017).

Accessibility, rather than a national strategy to unify services across Canada, has become the focus of Canada's current Liberal government. In June of 2018, Canada's federal government fulfilled an election promise by tabling the Accessible Canada Act, a new piece of legislation aimed at ensuring full accessibility for all Canadians (Globe and Mail, 2018). The Accessible Canada Act was tabled just before the House rose for the summer. It will not begin its way through the lengthy required additional readings and House and Senate debates until the fall of 2018 at the earliest. If/when passed, the Act will work to identify, remove and prevent barriers to access that fall under federal jurisdiction. Currently, the only provinces in Canada to have similar provincial legislation are Ontario, Manitoba and Nova Scotia. While the Government of Canada is to be commended for moving forward with an accessibility act, its avoidance of a national strategy that unifies services and supports for the disabled across Canada remains a concern.

While Canada's government appears to have dropped the priority of a national strategy, organizations that provide advocacy and support to people with disabilities have not. For example, the organization Every Canadian Counts (ECC) describe themselves on their website as "a coalition committed to improving services for Canadians living with long-term, chronic disabilities" (Every Canadian Counts, 2018) The ECC lobbies for a national disability strategy and, as such, they are "calling on Canadian governments to work together to develop a national program to ensure disability supports are available to all Canadians living with chronic, long-term disabilities" (Every Canadian Counts, 2018). Further, ECC asserts that thousands of Canadians with disabilities endure long wait lists and a lack of appropriate support that leads to individual and family crises including family breakup, homelessness, bankruptcy, etc. Another organization promoting the development of a national strategy for the disabled is the Council of Canadians with Disabilities (CCD). The CCD describe themselves as "a national human rights organization of people with disabilities working for an inclusive and accessible Canada"

(Canadian Council of Canadians with Disabilities, n.d.). On the social policy section of their website this organization asserts that it is time for change and indicates that the disability community has been calling for a national disability strategy that addresses the issue of disability supports in the short term and, in the longer term, addresses "the exiling of persons with disabilities to systems of income support that are both inadequate and ineffective" (Canadian Council of Canadians with Disabilities, n.d.). Similarly, Prince (2001) asserts that the top priority of the disability community is a national strategy on disability-related supports.

Development of a national strategy that would unify disability services and supports across Canada would likely mean revisiting and evaluating ways in which the federal and provincial governments could or should share the responsibility for the costs and implementation of such a strategy. However, both Canada's federal and provincial governments struggle under increasing fiscal deficits and the commitment of the Canadian people to maintaining welfare state policies is declining (Jongbloed, 2003). These factors, along with a brief history of federal/provincial relations relative to disability policy will be discussed in the next section.

Government Funding for Disability Supports in Canada

The economic model of disability became a significant driver of disability policy in the mid-twentieth century. The economic model of disability viewed disability as an economic and/or a medical deficit. As support for welfare-state policies grew in the 1950s and 1960s, Canada developed disability policies such as the social insurance system and the workers' compensation system. These monetary benefits were based on the premise that those who became disabled through work that helped to drive Canada's economy deserved compensation more than those whose disabilities were caused by other means (Hahn, 1985; Jongbloed, 2003). In his 2001 article, Prince notes that collaborative federalism was very much in evidence in disability policy making in Canada during the mid-twentieth century. Prince states that “the first main wave of disability policy making was during the 1950s and 1960s when several shared cost programs were established” (p. 794). This collaboration culminated in 1966, with the establishment of the Canada Assistance Plan (CAP). CAP was passed into law in 1966 (Moscovitch, 1988), and was intended to provide social support and programs to all persons in need, including the disabled (Jongbloed, 2003). CAP has been described as “perhaps the most harmonious product of the cooperative federalism period” (Dyck, 1976; Prince, 2001). When CAP was initially developed, federal and provincial officials were collaborative and consultative in its design (Prince, 2001).

The Canada Assistance Plan marked a change in Canada’s management of assistance programs, with its provision that the federal and provincial governments would jointly share fiscal responsibility for its implementation (Moscovitch, 1988). CAP was established in 1966 and represented the equal sharing of costs related to social programs between the federal and provincial governments of Canada (Moscovitch, 1988; Rock, 2017). Initially, given its ability to withhold funding from provinces that did not maintain social assistance policies that met federal expectations, CAP allowed the federal government to set national standards for the delivery of social assistance programs and policies. Over time, the federal government found equal cost sharing to be a significat financial burden and, in 1991, it imposed a limit on the amount the federal government would contribute to provincial social assistance. This funding change created an untenable situation, whereby the federal government was eventually shouldering only one third of the costs, while the provinces were bearing the additional two thirds (Rock, 2017). By 1996, CAP was replaced with a transfer system entitled the Canada Health and Social Transfer Program (CHST), which combined federal funding for health, postsecondary education and welfare into a specific amount of money for each province. Replacing CAP with a combined transfer program significantly reduced the ability of the federal government to set national standards for social programs and policies. It also reduced the ability of the provinces to pay for social services and programs as delivery of these programs needed to be managed within the allocated transferred funds (Rock, 2017).

The replacement of the Canada Assistance Program with the Canada Health and Social Transfer Program occurred under Jean Chretien's federal Liberal government and was implemented by Finance Minister Paul Martin. The CHST has been called "a child of federal deficit reduction" (Prince, 2001). McIntosh (2004) highlights the actual financial impact of the change from CAP to CHST. He notes that when CHST was first introduced in 1996, transfer payments from the federal government to the provinces dropped from just under $18.5 billion in fiscal year 1995/1996 to $14.7 billion in 1996/1997 (p. 31). This reduction created significant fraction between the federal and provincial governments and reduced the flexibility of provincial governments to fund health care and social services (p. 32). The increased focus on deficit reduction at the federal level that resulted in the change from CAP to CHST was also being reflected in the mandates of the various provinces, which had promised their electorates balanced budgets along with decreased tax rates and reduced deficits (McIntosh, 2004). The combined result of these intersecting but non-compatible realities was the inability for provinces to provide both health and social services that coincided with a mandate of fiscal restraint. This inability continues today.

1996, the year that CAP was replaced with the Canada Health and Social Transfer Program was also the year in which the Federal Task Force on Disability Issues produced the *Equal Citizenship for Canadians with Disabilities, The Will to Act* report. This report acknowledged that the federal government of the time was "engaged in discussions with the provinces and territories around appropriate roles and responsibilities for each level of government for the future, consistent with jurisdictional mandates, demographic trends, fiscal capacities and other factors" (pp. 13-14). The report went on to note that Canada's priorities were shifting and that this would "inevitably lead to further significant changes to social programs" (p. 14). However, the task force was hopeful that ongoing discussions might "identify some common areas for action and others where further negotiations will be necessary to achieve mutual agreement on how to address policy and program gaps" (p. 15). It appears that hope was misplaced as policy and program gaps relative to disability policy continue to be of significant concern, as identified in several of the preceding sections of this chapter.

The end of CAP and the introduction of CHST raised concerns about on-going support for the disabled. In an article written for the September/October, 1996 edition of the New Maritimes periodical, author Pat Dodson referred to the CHST as a "recipe for social disaster." Dodson highlighted the fact that the CHST was a block grant that could be spent at a province's discretion. The CHST was unlike the CAP, which earmarked portions of federal money for social assistance. Dodson speculated that provincial cabinets could now decide their own priorities and he reasoned that the needs of people with disabilities would be "pitted against those of every other provincial expenditure" (Dodson, 1996). Similarly, in an article written for the *Toronto Star* in 1995, author Sherri Torjman, then Vice-President of the Caledon Institute of Social Policy, lamented the loss of certain specific services that CAP provided to the disabled. Torjman noted that provinces would likely continue to fund some of these services but she predicted that "many social services will be cut back or withdrawn because CAP no longer will be in place to share any of the costs" (*Toronto Star*, June 14, 1995). A recent 2015 commentary on intergovernmental fiscal arrangements in Canada produced by the C.D. Howe Institute reaffirms the validity of these early concerns. Authors Robson and Laurin note that, after 2004, the CHST was further split into the Canada Health Transfer (CHT) and the Canada Social Transfer (SCT). Uncoupling these two components of the CHST was in direct response to public pressure to increase healthcare spending (Robson & Laurin, 2015), and using nomenclature that identified the portion the federal government intended for health care was a response to this pressure. Both the CHT and the CST are formally earmarked to support provincial spending on health care, education, child care, social assistance and other social programs. The reality, however, is that these federal transfers to the provinces are unconditional and provinces can spend them as they deem appropriate. The federal transfers can be used to fund services, provide tax relief or even improve the bottom line of provincial budgets. There have been no recent instances where Ottawa penalized a province for deficiencies in programs (Robson & Laurin, 2015), so there is no motivation for provinces to ensure consistent spending allocations.

Over time, transfers intended for health care have increased relative to transfers intended for social services. While social services transfers grew with the economy, health care transfers grew even faster, resulting in federal transfers that outpaced GDP. In recent years, one out of every three tax dollars raised by the federal government has been used to finance transfer payments to the provinces. In the fiscal 2014/2015 year, federal CHT transfers for health care were 32 billion and expected to increase to 41 billion by 2019/2020. In contrast, federal CST transfers for social services were 13 billion in 2014/2015 and expected to increase to 15 billion by 2019/20. Starting in 2017/18, the previous automatic 6 percent increase for social transfers ended, and increases to the CST are now tied to GDP growth rate, with a floor of 3 percent per year (Robson & Laurin, 2015). Similar constraints have not been put on transfers for health care.

However, this may be a moot point. As noted above, provinces are relatively free to spend transfer payments as they see fit, regardless of their intended allocation. This freedom to allocate transfer dollars creates a potential situation wherein programs and services for the disabled compete for dollars with all other areas of social services, as well as with the health care and education sectors.

As the foregoing discussion on the funding of disability services and supports clearly shows, the situation is complicated. The current transfer payments from the federal government for social services, including disability support, do not allow the federal government to set any type of national standards, as was possible under the older CAP system. The introduction of the CHST (now CST and CHT) was a cost cutting measure that eliminated the requirement for the federal government to pay for half the costs of health and social services. As the federal government sets only broad parameters on transfer payments, dividing them between health and social services, funds are not earmarked for any specific programs or services and provinces are free to spend them as they deem appropriate. Public support for increased social services competes with the need for fiscal restraint and debt reduction. As asserted by McColl and Jongbloed in the conclusion to their 2006 book, *Disability and Social Policy in Canada,* “the 1990s saw a shift toward valuing economic growth and deficit restructuring over issues associated with the evolving welfare state” (p. 405). This paradigm continues today as Canada’s governments work to balance funding for social services with fiscal restraint.

It should be noted that there may be mechanisms under which the federal and provincial governments could rework current funding arrangements for disability supports. Prince (2006) speculates that an entirely new federal transfer arrangement could be developed. He also suggests that a special fund, either within or outside of the current transfer funds is possible. His third suggestion is to adapt and build on the existing system. While all of Prince's suggestions are potentially viable, they fail to recognize the competition for funding that exists within health care, education, child care and social services. They also fail to recognize current fiscal realities and the lack of an influx of new funds. Overall, as this discussion on intergovernmental funding of disability services and supports has shown, the need and demand for disability services and supports requires funding commitments that, for various reasons, Canada's federal and provincial governments are unable or unwilling to meet.

Chapter Conclusion

The term 'hit-and-miss' has been used to describe the state of delivery of services and supports to Canada's disabled population. This term was first coined in 1977 by Joan C. Brown when the Canadian Council on Social Development asked her to describe and evaluate the disability services of the time. In 2004, Michael J. Prince asserted that the term was still an accurate assessment and descriptor. Numerous reasons exist for this on-going assessment. This chapter focused on three significant contributing factors to Canada's hit-and-miss approach to disability services and supports highlighted by Brown (1977) and Prince (2004). The first is the lack of a normative foundation, philosophy or model of disability that can be used to develop and evaluate disability policy. Without such a normative foundation, the ability to achieve consistent disability policy across Canada is very low. The second contributing factor is the lack of a national strategy to unify the differing practices that exist in the various provinces and territories across Canada. Without a national strategy, differences and inequities will inevitably remain in the various disability services and supports offered across Canada. The third and final significant contributing factor is the struggle on the part of Canada's federal and provincial governments to develop a funding mechanism for disability services and supports that ensures fair and equitable provision of services while also answering to and incorporating policies of fiscal restraint and debt reduction.

Note, that although these three contributing factors have been examined in this chapter mostly in isolation of one another, their inevitable interconnections are acknowledged. For example, the development of a normative foundation could potentially lead to the development of a national strategy. Should Canada look first to the development of a national strategy, doing so would require the development of some type of framework upon which to base that strategy. A funding mechanism for the outcomes associated with developing either a normative foundation and/or a national strategy would be essential. Essentially, then, tackling any of these three contributing factors could potentially mean exploring solutions to all three of them. If these factors were to be approached collectively, the resolution of all three could potentially provide powerful tools to enable a fair and uniform system of disability support across Canada. It is, however, an overwhelming task that would require unprecedented commitment, collaboration, a strong will to act and a healthy appetite for change.

In concluding this chapter, it is important to recognize that Canada has demonstrated a level of commitment to disability policy at both the federal and provincial levels. Numerous government publications attest to this. In fact, a background paper produced by the Parliamentary Information and Research Service, and authored by Chantal Collin (2012), lists 21 federal publications that were produced on topics related to persons with disabilities between 1981 and 2012. These papers, studies and reviews were produced under both Liberal and Conservative federal governments. Many similar provincial and intergovernmental papers, some noted and discussed in this chapter, have also been produced. Also, as mentioned in discussions above, Canada is making strides towards the implementation of a National Accessibility

Act. However, while Canada has demonstrated commitment to disability policy, it has never reached the level necessary to develop the normative foundation, national strategy and stable funding required to ensure Canada's investment in the disabled is no longer viewed as hit-or-miss.

This chapter has worked to provide the reader with an understanding of both the current and historical state of Canada's disability policy and legislation. As will be shown in the next several chapters, which describe and analyze the various components of my thesis research, the themes presented in this chapter are entwined in the analysis.

Chapter Five: Content Analysis of Canadian Newspaper Coverage of the Post-School Lives of Adults with Intellectual Disabilities

Print media has a long history as a powerful voice for informing society, framing opinions and drawing attention to important issues (Mao & Richter, 2014). Media coverage has the capacity to influence public understanding and perception, and the potential to incite political action (Wilson 1995; Boykoff & Rajan 2007; Jacobson, Langin, Carlton, & Kaid, 2012). Newsroom editors, and the corporations that employ them, decide which topics to cover and how much coverage to allot (White 1950; Reese & Ballinger 2001; Jacobson et al., 2012). As a result, the type and volume of information about the post-school lives of adults with intellectual disabilities which reaches the general public is determined, in large part, by the media.

The amount of coverage that a specific issue receives in the media has the ability to influence public opinion about its importance. This perceived importance, in turn, has the potential to influence agenda-setting at the public and political level (McCombs & Shaw 1972; Weaver et al. 2004; Jacobson et al., 2012). Given this, policymakers, policy influencers and public opinions are all influenced by the media (Mao & Richter, 2014). Additionally, the way the media frames a topic also affects public understanding. This is especially true for topics that are not part of the average person's daily life (Jacobson et al., 2012). Gamson and Modigliani (1987) describe a frame as "the central organizing idea or story line that provides meaning" (143). Public interpretation of an issue can be shaped significantly by the specifics of an issue that are emphasized by its framing in the media. As such, it is important to grasp how the post-school lives of adults with intellectual disabilities are framed by the media in order to understand how the public and political spheres may interpret their needs.

Media content analysis helps to answer questions about how social issues are communicated through the media, shines a light on what the media deems newsworthy, and highlights topics that can potentially influence policy makers (Mao & Richter, 2014). Krippendorff (2004) defines content analysis as a research technique that makes replicable and valid inferences from data derived from text. In his discussion of media research techniques, Berger (2012) describes content analysis as an “indirect way of making inferences about people. Instead of asking them questions, we examine what they read or watch and then work backward, assuming that what people read and watch are good reflections of their attitudes, values, and so on” (p. 24). Further, Bowen (2009) states that documents, such as media texts, can provide context, additional questions, supplementary data, a means of tracking change, and can verify the findings from other data sources.

While there is value in conducting a content analysis, Berger (2012) contends that there are two main limitations associated with this approach. First, Berger notes representativeness can be problematic in media content analysis because the volume of media available can make it hard to determine the right amount of material to study and a reasonable way to sample this material. However, Berger concludes that researchers navigate this potential problem by clearly setting inclusion and exclusion criteria for their study. Given this, I have carefully outlined and justified my source selection and inclusion criteria below. Second, Berger argues that there is no way to be sure that a media piece’s intended message, a media viewer’s interpretation, and the researcher’s findings are agreeable. Due to this reality, ‘reader response’ theories, which argue that media readers and creators play equally important roles in finding meaning in the media, have gained ground in recent years. As such, Berger emphasizes that media content analysts should be careful that they do not assume too much in their work. Thus, the content analysis undertaken in this research focuses on the content of the news stories examined but does not assume that all media viewers interpreted this content in the same way.

Standards for Selecting News Sources and Article Inclusion and Exclusion Criteria

For the purposes of this study, news articles concerning the post-school lives of adults with intellectual disabilities were compiled from the Canadian Broadcasting Corporation (*CBC*) and the *Toronto Star*. The *CBC* is the only publicly funded national news broadcaster in Canada. As a Federal Crown corporation, the *CBC* is mandated to "... incorporate a wide range of programming that informs, enlightens and entertains; be predominantly and distinctively Canadian [and to] reflect Canada and its regions to national and regional audiences…" (*CBC*, 1991). The *CBC*'s 2016/17 Annual Report indicates that, in 2015/16, the *CBC*'s digital news site averaged 12.4 million unique visitors monthly, and their market share for *CBC* Radio One and Radio Two was 18.5% (*CBC* 2016/17 Annual Report). Unlike the *CBC*, The *Toronto Star* is privately owned by a subsidiary of a large media and publishing company called the Torstar Corporation. The *Toronto Star* is currently Canada's largest daily newspaper and boasts the largest readership in Canada, with 1.6 million daily on-line readers and 2.2 million print readers (Powell, 2016). In its Statement of Principles, the *Toronto Star* notes that it "seeks to inform the public of the significant and interesting events of the day, with particular emphasis on politics and public affairs" (The Star, 2018). Given the *CBC*'s national public broadcaster status, and the coverage and reach of the *Toronto Star*, these two news sources were purposefully chosen for this analysis as they were deemed to provide accounts of newsworthy issues in Ontario and across Canada. Furthermore, as Casciotti et al. (2014) note, news stories which originate in high readership sources are often picked up by smaller outlets and further disseminated to regional audiences. Thus, it is likely that the average Canadian news reader engages with the content published by one or both of these sources.

The news articles examined in this research were identified using a relevance, or purposive, sampling approach. Krippendorff (2004) notes that this approach produces texts that are representative of the population of relevant texts rather than the population of texts as a whole. He contends that this is not probabilistic as only the textual units that do not possess relevant information are excluded. Using this purposive approach, the *Toronto Star* articles used in this analysis were retrieved by filtering the Canadian Major Dailies section of ProQuest to return results for the *Toronto Star* using the following terms: “development* disab* adult*” (121 results), and “development* disabil* transition” (50 results). Articles from the *CBC* were retrieved using the internal search tool available on the *CBC* news website (http://www.cbc.ca/search) and the same search terms used to search the *Toronto Star*: “development* disab* adult*” (247 results), and “development* disabil* transition” (46 results). As previously noted, the term ‘developmental disability’ encompasses intellectual disability and also includes physical disabilities. Consequently, the search term ‘development*’ was purposefully chosen to represent the broadest possible search.

As key-term searches are not flawless, search results were then filtered according to the following inclusion and exclusion criteria: (a) must be a text based article (i.e. video/audio posts with less than 250 words were excluded), (b) the primary focus must be the post-school lives of adults with intellectual disabilities, (c) must be in English, (d) must be published between June 2012 and June 2018. In the end, a total of 73 articles from the *Toronto Star* met all inclusion and exclusion criteria. These articles were an average length of 833 words (range: 210-2871). Using the same criteria, a total of 49 *CBC* articles, with an average length of 764 words (range: 257-1637) were identified.

The six-year time frame for this study was purposefully selected to capture coverage beginning with the 2012 launch of the Ontario Ombudsman investigation into situations of crisis involving adults with intellectual disabilities. Use of this time frame allowed for the exploration of a range of issues, facilitated an understanding of how media coverage changed over time, and avoided a possible reporting bias where coverage could be dominated by a particular event (Casciotti et al., 2014). In addition to hard news stories, editorials and letters to the editor were also analyzed to capture a range of perspectives of discussions relating to the lives of post-school adults with intellectual disabilities (Casciotti et al., 2014).

Analysis

Krippendorff (2004) notes that, because content analysts tend to use categories that are uniquely tailored to available texts, each content analysis is essentially started from scratch. As such, he argues that the results of one content analysis are not easily compared to another and consequently rarely advance theory. However, Krippendorff (2004) further contends that content analysts have a greater chance of drawing on and contributing to existing knowledge if they employ conceptualizations that have already been proven successful. To achieve this aim, he advocates that content analysts build on the instructions of published content analysis with similar aims. Given this, I have adapted the coding procedure used by Glenn, Champion, and Spence (2012) in their study of the news media coverage of weight loss surgery in Canada.

Glenn et al. (2012) applied four guiding questions to their content analysis, these included:

(a) what is the primary/dominant intent of the message?;

(b) who is speaking?;

(c) who is the target audience?; and

(d) what is the tone of the article? (p. 127)

Given that these guiding questions address the same themes that are important to my research, this model was deemed a good fit and was adapted to meet the needs of this study. As suggested by Glenn et al. (2012), all the identified articles were read prior to commencement of analysis in order to promote immersion into the topic and to insure the appropriateness of the guiding questions. As it was difficult to consistently determine the target audience of each article, this category was modified to examine the style of the article instead. Using the literary definition of writing style, news articles were coded as being either expository, persuasive, or narrative. The descriptive writing category was omitted as this style is more commonly found in fictional pieces.

Next, ten articles were randomly selected and coded by the researcher. Following this initial coding, four individual coding schemes were developed to address each of the four guiding research questions. Krippendorff (2004) notes that coding categories must be mutually exclusive and exhaustive, thus the coding schemes used in this research were fluid and updated as necessary throughout their initial development to ensure their rigor.

As advised by Mao and Richter (2014), after the initial coding I developed a frame by inviting two individuals outside this study to read a subset of news articles and code them. The frame was revised until a consensus was reached on the same coding categories at least 80% of the time. In their how-to guide regarding newspaper content analysis, Lynch and Peer (2002) make recommendations to the number of categories, to clearly define categories, and to remove any overlap between categories. Following this advice, the coding frame was finalized and piloted with a small sample of articles. I concluded at this point that the coding frame worked well and no further changes were made. The final coding frame used in this research is presented in Table 1.

Table 1

News Analysis Coding Schema

Guiding Questions	Theme
What is the primary topic of the article?	• Providing facts and information
	• Discussing long wait times for residential and/or day care for adults with intellectual disabilities
	• Discussing long wait times for and/or inadequate provincial funding for adults with intellectual disabilities
	• Discussing the inappropriate housing for adults with intellectual disabilities
	• Discussing employment opportunities for adults with intellectual disabilities
	• Discussing poor transition to and/or lack of services for adults with intellectual disabilities
	• Discussing the creation of a national autism strategy
	• Discussing child support for adult children with intellectual disabilities
	• Discussing cooperative housing for adults with intellectual disabilities
	• Discussing poor and/or inappropriate medical care for adults with intellectual disabilities.
Who is speaking (direct quotes in article)?	• Family members of adults with intellectual disabilities
	• Government representatives
	• Adult service representatives
	• Advocacy organization representatives
	• Scientific or medical representatives
	• Adults with intellectual disabilities
	• Ombudsman
	• Lawyers
	• Community members
	• None
What is the style of the article?	• Persuasive (call for change)
	• Expository (explain)
	• Narrative (personal story of struggle)
	• Narrative (personal story of success)
What is the tone of the article?	• Positive (focus on solutions)
	• Negative (focus on problems)
	• Mixed (focus on problems but hopeful for solutions)
	• Neutral (none of the above)

After the development of the coding schema, a line-by-line thematic coding according to the four guiding questions was undertaken on each individual article. A maximum of two primary topics, indicated by the title and the focus of the story, were selected for each article. Additionally, the event prompting the story and the article characteristics (date published, page location, word length, news versus op-eds, author and authors typically area of focus) were recorded.

Findings

All the articles included in this study were analyzed according to the coding schema outlined in the previous section. The statistical results of this analysis can be found in Table 2 and are described in detail below.

Table 2

Characteristics of Newspaper Articles Discussing Adults with Intellectual Disabilities

	Toronto Star		CBC		Overall Sample	
Newspaper Articles	N	%	N	%	N	%
Sample	73	60%	49	40%	122	100%
Type of Article:						
News Article	61	84%	49	100%	110	90%
Opinion/Editorial	12	16%	0	0%	12	10%
Article Location:						
Front page (of section or paper)	38	52%	-	-	-	-
Other location	35	48%	-	-	-	-
Authors Area of Focus:						
Social Justice	29	40%	-	-	-	-
Education	13	18%	-	-	-	-
Editorial columnist	12	16%	-	-	-	-
General Assignment	7	10%	-	-	-	-
Feature writer	4	5%	-	-	-	-
Politics	3	4%	-	-	-	-
Other	10	14%	-	-	-	-

Table 2 – *Continued*

	Toronto Star		CBC		Overall Sample	
Newspaper Articles	N	%	N	%	N	%
Year Published:						
2012(Jun-Dec)	17	23%	1	2%	18	15%
2013	8	11%	5	10%	13	11%
2014	15	21%	7	14%	22	18%
2015	4	5%	8	16%	12	10%
2016	10	14%	14	29%	24	20%
2017	14	19%	6	12%	20	16%
2018 (Jan -Jun)	5	7%	8	16%	13	11%
Article Topic (up to 2 per article):						
Discussing long wait times for residential and/or day care for adults with intellectual disabilities	21	29%	24	49%	45	37%
Discussing poor transition to and/or lack of services for adults with intellectual disabilities	15	21%	19	39%	34	28%
Discussing long wait times for and/or inadequate provincial funding for adults with intellectual disabilities	17	23%	13	27%	30	25%
Providing facts and information	17	23%	4	8%	21	17%
Discussing the inappropriate housing for adults with intellectual disabilities	10	14%	10	20%	20	16%
Discussing cooperative housing for adults with intellectual disabilities	5	7%	6	12%	11	9%
Discussing employment opportunities for adults with intellectual disabilities	6	8%	3	6%	9	7%
Discussing child support for adult children with intellectual disabilities	6	8%	0	0%	6	5%
Discussing poor and/or inappropriate medical care for adults with intellectual disabilities	3	4%	2	4%	5	4%
Discussing the creation of a national autism strategy	2	3%	0	0%	2	2%
Tone:						
Positive (hopeful)	10	14%	6	12%	16	13%
Negative (focus on problems)	28	38%	22	45%	50	41%
Mixed (focus on problems but hopeful for solutions)	34	47%	20	41%	54	44%
Neutral (none of the above)	1	1%	1	2%	2	2%
Style:						
Persuasive (call for change)	17	23%	7	14%	24	20%
Expository (explain)	36	49%	13	27%	49	40%
Narrative (personal story of success)	4	5%	6	12%	10	8%
Narrative (personal story of struggle/hardship)	16	22%	23	47%	39	32%

Table 2 – *Continued*

	Toronto Star		CBC		Overall Sample	
Newspaper Articles	N	%	N	%	N	%
Event Prompting Story:						
Family in Need	18	25%	19	39%	37	30%
Report	16	22%	6	12%	22	18%
Funding	15	21%	5	10%	20	16%
General Interest	7	10%	10	20%	17	14%
Legal Challenge	7	10%	4	8%	11	9%
Other	10	14%	5	10%	15	12%
Voice (direct quotes):						
Family members of adults with intellectual disabilities	44	60%	41	84%	85	70%
Government representatives	36	49%	23	47%	59	48%
Adult services representatives	16	22%	16	33%	32	26%
Advocacy organization representatives	10	14%	10	20%	20	16%
Scientific or medical experts	14	19%	4	8%	18	15%
Adults with intellectual disabilities	13	18%	5	10%	18	15%
Ombudsman	8	11%	2	4%	10	8%
Lawyers	7	10%	0	0%	7	6%
Community members	5	7%	0	0%	5	4%
None	1	1%	2	4%	3	2%

Of the 122 articles analyzed in this study, 60% were published in the *Toronto Star* and 40% were published by the *CBC*. Although at first glance it would appear that the *Toronto Star* allotted significantly more coverage to this topic than did the *CBC*, it should be noted that many relevant video and audio posts made by the *CBC* did not meet the inclusion criteria of 250 words for this research. Further, *CBC* News does not publish opinion or editorial pieces which contributed to an overall sample consisting primarily of hard news articles (90%).

CBC publishes its news articles exclusively online and typically indicate an article's importance by placing it at the top of its news feed. Unfortunately, the original position of an online news article cannot be historically traced. As such, it was only possible to retroactively search the location of articles printed in the *Toronto Star* (see Table 3). Of these, 52% of the stories appeared on the front page of the paper (25%) or on the front page of their respective sections (27%). In their 1977 study on newspaper readership, McCombs and Mauro found that page location and the amount of space allocated to an article are the two biggest predictors of article readership. Further, Reisner (1992) contends that the front page is the most important page of a newspaper as it contains the articles that are most likely to be read, and also suggests to readers what the newspaper considers to be the most important stories. Thus, while only an average of 10 articles concerning the adult lives of individuals with intellectual disabilities were published each year by the *Toronto Star*, half of these stories were deemed important and relevant enough to secure this top position.

Table 3

Characteristics of Front Page Articles Discussing Adults with Intellectual Disabilities

		Front Page of Paper		Front Page of Section		Overall Sample of Front Page Articles	
	Front Page Newspaper Articles	N	%	N	%	N	%
	Sample	18	47%	20	53%	38	100%
Article Topic (up to 2 per article)	Discussing long wait times for residential and/or day care for adults with intellectual disabilities	7	18%	5	13%	12	32%
	Providing facts and information	3	8%	8	21%	11	29%
	Discussing the inappropriate housing for adults with intellectual disabilities	3	8%	4	11%	7	18%
	Discussing long wait times for and/or inadequate provincial funding for adults with intellectual disabilities	4	11%	2	5%	6	16%
	Discussing child support for adult children with intellectual disabilities	2	5%	4	11%	6	16%
	Discussing poor transition to and/or lack of services for adults with intellectual disabilities	1	3%	2	5%	3	8%
	Discussing employment opportunities for adults with intellectual disabilities	1	3%	1	3%	2	5%
	Discussing poor and/or inappropriate medical care for adults with intellectual disabilities	1	3%	1	3%	2	5%
	Discussing cooperative housing for adults with intellectual disabilities	0	0%	1	3%	1	3%

Although the media itself maintains a commitment to unbiased reporting, critical research on media and policy is grounded in an understanding that meaning is produced, rather than simply reflected, by the media (Cohen, 2010). Thus, Burns et al. (2008) define agenda setting as it relates to the media as "the ability of the mass media to set the agenda for public discussions" (p. 604). They argue that media agenda setting "influences public agendas and policies through deliberate coverage of events and issues, with the media prompting policymakers to take action and satisfy the public's interest or demand for answers" (p. 604). Nearly half (48%) of the front page articles, and roughly two thirds (62%) of all of the articles analyzed in this study told the story of long wait times for housing, day services or provincial funding faced by the families of adults with intellectual disabilities. Similarly, half (50%) of these front page articles were prompted by a family's immediate need for help in caring for an adult child with an intellectual disability. Thus, it could be surmised that the *Toronto Star* is calling on policy makers to address the needs of these families. This assertion is further evidenced by the fact that the *Toronto Star* has published numerous articles under the banner of its 'Autism Project'. The Autism Project was a Michener Award nominated series that aimed to "overhaul the province's autism policies" (Slaughter, 2013) and is acclaimed by the Michener Awards Foundation (2013) for having "sparked an intense debate and put questions about policy and treatment squarely on the political agenda" (Slaughter, 2013).

While its lead articles cannot be identified, the *CBC* News articles analyzed in this study can also be seen to promote the welfare agendas of individuals with intellectual disabilities and their families. Many of the *CBC* articles included in this research were published under the *CBC*'s *Crisis of Care* initiative. Inspired by the story of one family's needs, this series was spearheaded by the host of *CBC*'s White Coat, Black Art a weekly program that "takes listeners through the swinging doors of hospitals and doctors' offices" (*CBC*, 2018). *Crisis of Care* featured the struggles faced by the parents of special needs children as they aged out of educational and pediatric systems. Nearly two fifths (39%) of the *CBC* articles included in this study were related to this issue, which indicates that the *CBC* chose to put stories featuring a family's immediate need for help in caring for an adult child with an intellectual disability at the forefront of their news coverage.

The *CBC* did not indicate authorship for 45% of the articles analyzed in this study as the *CBC* does not typically note the specific areas of focus of its reporters. Accordingly, the authors' area of focus was only calculated for the articles that appeared in the *Toronto Star*. Of these, 40% were written by social justice columnists, 18% were written by education columnists and 16% were editorial pieces. The remaining articles were assigned to general assignment reporters (10%), feature writers (5%) and politics reporters (4%), with the final 14% falling into columns that only appeared once, such as cannabis and science and technology. These were grouped together under an 'other' category.

According to the National Association of Social Workers, social justice can be defined as "the view that everyone deserves equal economic, political and social rights and opportunities" (NASW, 2008). Given that the bulk of the *Toronto Star* articles in this study were attributed to social justice reporters, the evidence signals that the *Toronto Star's* coverage of issues faced by adults with intellectual disabilities is advocating that policy makers ensure that the rights of this demographic are upheld. In this way, the *Toronto Star* can be seen to advocate for a human rights model of disability in that it purports that all persons with disabilities have a right to be legally recognized as a person before the law. In his writings on social justice, Bankston (2010) contends that the principles of social justice are often used as a "vague slogan or rallying cry" (p.

175). Viewed in this way, the *Social Justice* byline which accompanied nearly half of the *Toronto Star's* articles analyzed in this study can be interpreted as a prompt encouraging people to unite and to act in support of adults with intellectual disabilities.

Andelsman and Mitchelstein (2018) characterize framing as "the tool journalists have to select certain aspects of reality and make them more visible in the text, to promote a particular problem definition, causal interpretation and/or recommend solutions" (p. 5). Underpinning framing theory is the assumption that the same issue or event can be presented in different ways and that this presentation directly affects how the audience thinks about it (Chong and Druckman 2007; Entman and Rojecki 2001; Scheufele 1999). Give this, the tone and style of the identified articles were analyzed for their optimism and writing style. Two fifths (41%) of the articles examined in this study were deemed to have a negative tone and focused primarily on the problems faced by adults with intellectual disabilities and their families, while just 13% of the articles were predominantly hopeful in nature. An additional two fifths (44%) of the articles presented a mixed tone which focused on problems but were also hopeful for solutions. From this analysis, I concluded that both the *Toronto Star* and the *CBC* have chosen to largely problematize the adult lives of individuals with intellectual disabilities and have steered reader focus toward their currently unmet needs.

According to the American Press Institute (2018), "news is that part of communication that keeps us informed of the changing events, issues, and characters in the world outside. Though it may be interesting or even entertaining, the foremost value of news is as a utility to empower the informed." Hence, it follows that expository articles, which explain a concept or impart information, represent two fifths (40%) of the articles in this study. The phenomena known as *schadenfreude* has long been studied by psychologists and represents the self-satisfaction derived from the misfortune of others. In their research on *schadenfreude* in the media, Gao et al. (2014) contend that the media utilizes real-life misfortune for the purposes of entertainment. Further, Zillman et al. (2001) note that people are more likely to skim a magazine featuring cover stories of others' misfortunes. Given this, it could be stated that the *Toronto Star* and the *CBC* are banking on schadenfreude as nearly one third (32%) of the articles examined were narrative in nature and told a personal story of struggle and hardship while only 8% focused on a story of success. Finally, the remaining 20% of the articles analyzed were deemed to be persuasive and represented a call for change from various stakeholders in society.

According to Freedman and Suita (2006), reporters rely on subject matter experts "first to gain a better understanding of a complex issue and, second, to convey to their audiences an insight or opinion that is credible" (p. 48). Given this, it follows that an overwhelming 70% of the articles examined in this study directly quoted the family members of adults with intellectual disabilities as their personal experiences would undoubtedly make them experts in this field. All the article topics addressed in this research have direct links to governmental policy. Accordingly, government representatives can be seen to represent subject matter experts in this field and are quoted in nearly half (48%) of the articles analyzed in this study. Given their direct involvement with adults with intellectual disabilities, it follows that adult service representatives and advocacy organizations are quoted in just over two fifths of the articles (42%). Interestingly, only 15% of the included articles quote scientific or medical experts or feature the quoted voices of adults with intellectual disabilities. While it is unknown why so few of the articles relied on scientific or medical experts, it could be concluded that there are inherent attitudinal and structural barriers to the full participation of people with intellectual disabilities (Chappell, 2000), thus, their voices are often omitted.

Chapter Conclusion

Media interest in the lived experiences of adults with intellectual disabilities and their families represents an important source of data that may be useful in understanding how broader societal factors may influence policy development concerning this issue. The forgoing analysis provides a retrospective examination of the media's coverage of, and its portrayal of, the needs of adults with intellectual disabilities and their families. With nearly two thirds (62%) of the included articles focusing on long wait times for housing, day services or provincial funding faced by the families of adults with intellectual disabilities and a further one third (28%) directly addressing the rocky transition to adult services, it can be concluded that the *Toronto Star* and *CBC* News are lobbying policy makers to address what has become known as the period in which adults with intellectual disabilities embark on a *bridge to nowhere* as they age out of the school system and begin to navigate the murky world of adult services and seemingly endless waitlists.

This chapter provided the reader with details of the media coverage relative to the post-school experiences of individuals with intellectual disabilities. To help provide context, the next chapter will provide overviews of interviews that I conducted with two government representatives and a representative from a community organization.

Chapter Six: Contextual Interviews

In order to provide context to this research, this chapter will detail overviews of my conversations with Senator Jim Munson and an Education Officer with the Ministry of Education. Further, it will detail my conversation with a representative from the Family Matters Cooperative. Note that all three of these individuals provided consent and were aware that the conversations I conducted with them would be used for this research. Further, all were made aware that they could request to view transcripts of our conversations but, to date, only the Education Office has requested this access.

Contextual Interviews

Interview with Senator Jim Munson.

Jim Munson was called to the Senate in December, 2003, as a representative of the province of Ontario. Since becoming a Senator, Munson has been a champion of issues related to the well-being of children, children with autism and the Special Olympics (CPAC, 2016). He is best known for his work to pass the *World Autism Awareness Day Act* and the ground-breaking Senate report *Pay Now or Pay Later: Autism Families in Crisis* (Senate of Canada, 2018). Given that Senator Munson is a champion for youth, and a representative of Canada's federal government, I anticipated that his input and opinion would help to inform and provide context to this research. I therefore requested an interview with him and, after several follow-up e-mail exchanges, I was able to meet with Senator Munson in his office on January 23, 2019. The results of this interview are outlined below.

I began by asking Senator Munson if he believed that anything could be done to make it easier for adults with intellectual disabilities and their families to access the services and supports provided by the government. In response, Munson spoke at length about how he, along with the greater autism and intellectual disability community, worry that we are building a bridge to nowhere. In this regard, Munson passionately stated:

> It's very disturbing, and it's shocking that we're not building that bridge to a better place as opposed to a bridge to nowhere. You'll find that concern all across the country. You lose your pediatrician, you lose, you lose so many things that you have up until age 21 or 18. And it is my view, and it's always been my view, and I pushed forward with that report in the Senate, that the federal government has to take a more hands-on approach. To build that bridge to somewhere in collaboration with the provinces.

Munson expressed grave concerns about the loss of services faced by individuals with intellectual disabilities when they reach adulthood. His words echo the concerns expressed by the participants in this study who were struggling to overcome, and find suitable replacements for, the loss of services that happened when their children aged out of school.

Munson focused specifically on housing and meaningful inclusion when speaking of the challenges faced by young adults with intellectual disabilities as they transition to adulthood. Munson is an active member of the Canadian Autism Spectrum Disorder Alliance (CASTA) and he noted that housing is a major issue that this organization is working to address. In discussing the housing situation, Munson contended that families have “lost hope,” and he offered this sad lament:

> And here we are thinking now ‘but what do we do?’ Well, we should be creating group homes. But what do we do in the group homes? How do we work out that these young men and women, who are now beyond the age of receiving the programs they had up until 21…do they go into a group home and play video

> games? Do not very much with their lives? Or is there a component where you can actually motivate them, enable them, into positive lines of work?

The loss of hope that Munson refers to is evidenced by the 22 year long waiting list that families face when attempting to access housing for their adult children with developmental disabilities (Spagnuolo, 2016). The housing crisis is further exacerbated by the fact that, in Ontario, privately operated and publicly funded group homes are permitted to set their own eligibility criteria for admitting residents and are also permitted to evict residents whose evolving needs and/or behaviours are deemed to fall outside of the admissions criteria. These selective admission and eviction criteria often result in the exclusion of those with the highest needs (Spagnuolo, 2016). The parents who participated in this research also shared Munson's concerns that individuals may not be offered the fullest life possible in group homes and voiced concerns about leaving their children to stagnate in day and residential programs. Along this line, Munson argued that we don't just need to create housing, we need to create "housing that matters [where] there is somebody living within that group home, our house, that has the ability to nurture, an ability to teach, an ability to connect."

I asked Senator Munson if he felt the Ontario government could better support young adults with developmental disabilities as they transition out of youth services. He responded, "yes, absolutely" and went on to say:

> I'm concerned, presently anyway, with the political makeup in my province right now. And I don't like to have politics enter into the discussion that we're having. Because we're talking about people's lives. But when you're looking at cuts, that seems to be the easiest place to cut. It seems that the vulnerable become more vulnerable. That when it comes to issues like child health, child care, when it

> comes to issues as Francophone rights, when it comes to issues as the environment… and the list goes on. I recognize the deficit or debt that we have. But why does it have to be at the expense of those who need more money, more programs and more initiatives for people who have a disability.

As previously discussed in the chapter on policy and legislation, the Canada Assistance Program (CAP) was replaced with the Canada Health and Social Transfer Program (CHST) under Jean Chretien's federal Liberal government in 1996. CHST has been called "a child of federal deficit reduction" (Prince, 2001) as it saw transfer payments from the federal government to the provinces drop by nearly 4 billion dollars in the first year it was introduced (McIntosh, 2004). This reduction created significant friction between the federal and provincial governments and reduced the flexibility of provincial governments to fund health care and social services (McIntosh, 2004). The increased focus on deficit reduction at the federal level that resulted in the change from CAP to CHST was also reflected in the mandates of the various provinces, which had promised their electorates balanced budgets along with decreased tax rates and reduced deficits (McIntosh, 2004). The combined result of these intersecting but non-compatible realities was the inability of provinces to provide both health and social services that coincided with a mandate of fiscal restraint. This inability continues today and has resulted in many of the service cuts that Munson speaks of.

Noting that autism is a medically diagnosed condition, Munson argues that the government should not put restrictions on the funding and services that people with autism receive. He stated:

> I don't quite understand why we're not spending more. I don't know why people have to say there's a price tag on this issue when you're talking about people's

> lives with autism. Because we never question, if you or I walked into a hospital saying "my heart is having trouble... my chest, and so on and so forth" automatically the system kicks in. So "my God you have to have a stent or my goodness you have to have this done." What are we going to do? There's no question about it. And none of us sit back and write a cheque. It happens. It's done.

To provide this funding, Munson pointed to the necessity of a tax increase and stated that “the rest of us will have to, you know, care through taxes, more tax, whatever the case may be.” While this may indeed be the case, tax increases are not popular among the electoral base and federal and provincial governments are left trying to balance growing debts with growing needs, fiscal responsibility and hope of re-election.

On several occasions throughout our conversation, Senator Munson made reference to the creation of a National Autism Strategy. It should be noted, however, that Canada has not created a national strategy for any disability. While Munson argues for a national policy on autism, one could question the logic and functionality of isolating autism from other disabilities on a federal policy level. In addition, as discussed in the policy and legislation chapter, there is advocacy for a national disability strategy that doesn’t isolate any one diagnosis or disability. To underscore the need for federal and provincial collaboration, Senator Munson drew my attention to the Senate Report *Pay Now or Pay Later: Autism Families in Crisis*. He indicated that, while this report is now eleven years old, the key recommendation, which was the establishment of a comprehensive National Autism Spectrum Disorder Strategy, has not yet been achieved. Munson declared:

> For the life of me, I keep pushing for a National Autism Strategy. Because there are too many groups - and I keep referring back to autism and the disability community - who are working in silos. And, as you probably well know, in some provinces there are more activities and programs for those adults with autism or other intellectual disabilities than others […] I don't want to live in Mahoney Bay Nova Scotia and not be able to do anything… But there may be something for me in British Columbia. I really don't want to move. Why can't it happen here? And I think that's the crisis that we're in.

When CAP was scrapped in 1996, it was called a "recipe for social disaster" (Dodson, 1996) as, along with reducing the amount of funding allocated to the provinces, the federal government also reduced their ability to influence how the provinces would spend the money allocated to them for education, health care and social services. Essentially, Munson argues for a return to CAP era policies as he contends that the "federal government should tell provinces 'you get this money and we believe this is how you should spend it."

Shortly before our interview, the Centre Block of Parliament closed for a 10-year renovation. With this closure, Senator Munson's office was relocated to a freshly refurbished office across the street from Parliament Hill. Munson's office was stark and he told me that he had barely begun the task of unpacking his boxes. At the end of our conversation he pointed to a solitary frame that had been hung on the wall of his office. He spoke with passion and pride about his work to have World Autism Awareness Day recognized in law, and said:

> Can you imagine that? That's the Bill there behind you and that's the law right now. And it took three years for that simple law to get passed because another government wanted me to drop it. And say, well you should just have a minister

> have a decree saying April 2nd is World Autism Awareness Day. No, when you have it as law, it has a sense of empowerment.

While I am proud to have a Senator who is a zealous advocate for the rights of individuals with intellectual disabilities, the end of my conversation with Senator Munson left me wondering if meaningful changes to Canada's disability policy are foreseeable given that it took three years to pass the World Autism Awareness Day Bill. The passing of this Bill required only agreement and the stroke of a pen, not the billions of dollars in funding that is so badly needed by the intellectual disability community.

Communications with the office of the Ontario Minister of Education.

I began my efforts to speak with Ontario Minister of Education, Lisa Thompson, by emailing an interview request to her constituency office on October 18, 2018. In case a formal meeting was not possible, I also included two questions that I asked that the Minister, or someone from her office, respond to in writing. These questions were:

1. How does the transition planning that occurs in Ontario's schools prepare young adults and their families for the transition from school to post school life?
2. What is the biggest challenge that exceptional young adults and their families face once they graduate or age out of the Ontario school system?

I received a telephone message on December 12, 2018 from the Program Implementation Branch of the Ministry of Education providing me with contact information for an Education Officer with the Ministry of Education. After leaving a message for the Education Officer on December 13, 2018, she returned my phone call on December 14, 2018. Unfortunately, I was unable to record this phone call. I did, however, take extensive notes.

The Education Officer initiated the phone conversation by indicating that she had prepared an answer for my first question only. She stated that the second question was an opinion question and answers would differ from community to community and would also be dependent on the diagnosis of the individual student. Further, she asserted that the Ministry does not use the phrase ‘age out of the system’ as they believe that everyone is a life-long learner.

In response to my first question, the Education Officer indicated that the *Creating Pathways to Success* policy document is followed by the school boards and its guiding principles are used to frame educators’ interactions. She noted that this document does not lay out specifically how to use the policies for special education. She went on to further note that her area of specialty is not special education and that she would pass along the questions to a special education specialist who might be able to provide a more fulsome response.

The Education Officer asked me specifically about my research and she expressed the perspective that what I was doing was valuable and could potentially bring about change. While she did not have specifics, after learning more about my research, she noted that the Ministry of Education provides funding transfers and grants to communities that could potentially be used to better support special needs students before and during their transition from school to post-school life. The Education Officer ended our conversation by indicating that she would send a brief summary of our conversation by email and that she would send the questions along to someone in special education who might be able to give more insight.

In response to my first question about how the transition planning that occurs in Ontario's schools prepares young adults and their families for the transition from school to post school life, the Education Officer provided the following email response:

The Ministry recognizes the importance of preparing our students to graduate with the skill and knowledge requirements they will need to be successful in school, work and life. Students are provided with foundational skills based in curricular expectations coupled with rich experiential learning opportunities that connect the real world to what they're learning in school. These aspects of a student's educational experience serve to inform the development of a plan to pursue postsecondary education or training and the competence and confidence to adapt their plans as they and the world around them change.

Ontario's career development policy, Creating Pathways to Success: An Education and Career/Life Planning Program for Ontario Schools, 2013 (CPS), provides the program framework to support students as they transition through school to their postsecondary destination - whether it is to obtain training in the skilled trades, or to attend college or university, either directly or after some time spent in the workforce.

This is a comprehensive, whole-school program delivered through classroom instruction linked to the curriculum and through broader school programs and activities for students from Kindergarten to Grade 12.

The vision of the program is that "All students should leave secondary school with a clear sense of self and a plan for their initial postsecondary destination and with confidence in their ability to implement and revise or adapt their plan throughout their lives as they and the world around them change. This vision sees students as the architects of their own lives" (page 6).

> The program is framed by a four-step inquiry process based on four questions linked to four areas of learning:
>
> - Knowing Yourself - Who Am I?
> - Exploring Opportunities - What Are My Opportunities?
> - Making Decisions and Setting Goals - Who Do I Want to Become? and,
> - Achieving Goals and Making Transitions - What is My Plan for Achieving My Goals?
>
> Boards and schools provide multiple, varied, age and developmentally appropriate opportunities for students from Kindergarten to Grade 12 to develop personally meaningful answers to these questions as they acquire the skills, knowledge and habits of mind associated with effective education and career/life planning.
>
> These opportunities range from curriculum-related career exploration activities to specialized programs such as Specialist High Skills Majors, dual credits, or cooperative education to school and community activities such as industry visits, speakers and job fairs. Through these opportunities, students get a sense of where their strengths and interests lie and what is out there for them.

Exploring my communications with the office of the Ontario Ministry of Education.

As noted previously, the Communications Officer with the Ontario Ministry of Education requested to view transcripts of our conversations and to approve the final text included in this thesis. Consequently, a redacted version of what was originally written is presented above. As the Education Officer indicated that the redaction was intended to offer a factual, rather than descriptive representation of my contact with the Ontario Ministry of Education, I have chosen to explore this communication separately from the text above in order to ensure that my analysis is not mistaken for descriptive representation of our conversation.

Klein, Tye and Goodlad (1975) propose five different perspectives of the curriculum: ideal, formal, perceived, operational and experiential. According to the authors, the ideal curriculum is that which is built on the best available knowledge. However, given that educational ministries, school boards and textbook publishers operate within fixed budgets, they propose that the formal curriculum, that which is approved by the government, emerges as a less-complete version of the ideal. From there, teachers interpret the curriculum based on their varied backgrounds, professional training, value orientations and ongoing assessments of student needs. Consequently, Klein, Tye and Goodlad propose that the perceived curriculum is that which teachers perceive was mandated by formal curriculum while the operational curriculum represents what individual teachers are actually teaching. Finally, they propose that the experiential curriculum is that which is experienced by the students. Essentially, this is the level at which students make meaning.

The *Creating Pathways to Success* policy document which the Education Officer referred to in our telephone conversation and referenced extensively in her email can be seen to represent what Klein, Tye and Goodlad (1975) refer to as the formal curriculum as it is The Ministry's approved policy based on research and best practice. However, as the Education Officer pointed out that this document does not lay out specifically how to use the policies for special education, it can be concluded that Ontario's transition practices fall into the perceived and operational curriculum levels as teachers must interpret how to use these policies to best meet the needs of their students and then apply them on a practical level. Finally, the Education Officer noted that the vision of the *Creating Pathways to* Success policy is that:

> All students should leave secondary school with a clear sense of self and a plan for their initial postsecondary destination and with confidence in their ability to implement and revise or adapt their plan throughout their lives as they and the world around them change. This vision sees students as the architects of their own lives (p. 6).

While the intentions of this policy are sound, what students actually leave secondary school with is likely rooted in the experiential curriculum experienced by students in the form of their inclusion in their own IEP process along with the provision of meaningful opportunities for students acquire the skills and knowledge necessary to meet their transition goals.

Following a similar path, Elliot Eisner (1994) divided the school curriculum into three essential, ubiquitous forms: explicit, implicit and null. According to Eisner, the explicit curriculum concerns the learning opportunities that are overtly taught, stated or printed. Essentially, this is precisely what the school advertises that it does. Conversely, Eisner proposes that the implicit curriculum, or hidden curriculum, is not stated or written down. It represents the lessons which are learned by students but which are not openly intended by educators, such as the transmission of social norms, values and beliefs conveyed through the classroom and social environment. Lastly, Eisner suggests that the null curriculum represents that which the students are not given an opportunity to learn. This can include under-taught, arts based subjects, or the absence of certain experiences, interactions and/or conversations. For example, if students are not taught to critically think about inherent racism or sexism in text books, they are, by default, learning something about societal values.

Analyzed in this way, the *Creating Pathways to Success* policy document can be seen as the explicit curriculum while the implicit curriculum is inherent in the range of educational, employment, social and other opportunities that students with intellectual disabilities are given access to at school. Further, the null curriculum can be found in an individual student's classroom placement, grouping, inclusion or exclusion in the school community, etc

Interview with the Families Matter Cooperative.

The Families Matter Cooperative (FMC) is an Ottawa based cooperative that was founded in the early 2000's to offer support, information, networking opportunities and innovative solutions to families who support loved ones with developmental disabilities (Families Matter, 2014). According to its website, the FMC "serves families that are starved for information on how they can work on their own and with others in the community to build and fashion the resources and supports that their loved ones require to be an included part of Ottawa" (Families Matter, 2014). Further, the FMC's website contends that "families are anxious for the guidance to construct the innovative solutions to provide meaningful daytime activities, safe social interaction and appropriate supported housing" (Families Matter, 2014). The FMC plays an active role in supporting and providing information to families as their children with developmental disabilities come of age. I reached out to the FMC and requested an interview to gain additional insight into the types of supports that families are asking for as their children age out of school. I was given the opportunity to speak to one of the founding members of the FMC, Marge McCabe, at her home in Ottawa in August 2018.

Marge is the mother of an adult daughter with an intellectual disability and is a passionate and active member of the disability community in Ottawa. I began our conversation by asking Marge how she got involved in the FMC. She replied:

> Well, all of our kids were coming out of school. And once you're out of the educational system there is no legislation that makes anyone responsible. The

> funding is all by luck or by initiatives or by whatever. So my husband gets transferred back [to Ottawa] just as [our daughter] was finishing up high school. So of course, I'd been active in Saskatoon and Ottawa and Sudbury and wherever, because you have no choice. So I came back here and I started to look for parents who have the same issues as us. I was trying to get her back into the system, so I connected with parents who were very strong and very active. We knew we had to do some strong advocacy so we started the Families Matter Co-Op."

Throughout our conversation, Marge referred several times to the fact that the FMC serves to provide families with a louder voice with which to advocate for their children. She told me that when she returned to Ottawa she found that there were very few networks in Ottawa for families who cared for loved ones with intellectual disabilities. As she networked, however, she found other families with similar needs. She described the initial intent:

> So as a group of families we decided, okay we need to form, we need to form a charitable non-profit thing so that we can have a bigger voice. So that's how Families Matter Co-Op started. It really was only for connecting families to each other. Families can never connect through the system. The system knows everything about everyone. But families are down here trying to figure out who knows what and how to navigate this. But no one ever connects everyone together."

The creators of the FMC found that they were more successful in accessing services for their children when they worked together and supported each other. This finding holds true today as the FMC's diverse board and membership continue to work together to affect change and support one another.

I asked Marge how the FMC supports families as their children with intellectual disabilities age out of the school system. She passionately responded, “It's a nightmare. You've probably already got that. You’ve probably already got that message, that it's a nightmare.” She went on to talk about how she feels the transition is particularly difficult because education is a legislated right while the services that adults receive after leaving school are more piecemeal. She noted that:

> I'm only saying how disjointed coming out of that system and ending up here, where there's nothing. Education is legislated. Everything after that is not legislated. It's all by what politician is in power and what initiative they want to give.

I asked Marge if she thought that schools were doing enough to support students with intellectual disabilities as they age out of school. She responded by talking specifically about what she sees as the discrepancy between the IEP planning that happens in school and the implementation of that plan that happens after school. Marge said “I've heard a hundred plans. There's no implementation because there's no funding.”

The lack of legislated supports for adults with intellectual disabilities was a key theme during my conversation with Marge. Time and again, she pointed to the fact that she felt that true progress for the intellectual disability community requires legislative changes. When I asked Marge what changes she would make to better support families as their children age out of school, she responded:

> If there's one thing I could change, legislate support services for people with developmental disabilities. That's how that happens. Otherwise, there is going to

> be inequities and there's going to be long waiting lists and there's going to be 80-year-old parents with a developmentally disabled child.

Marge contended that if services for adults with developmental disabilities were legislated then the "fall off the cliff wouldn't happen because there would have to be something in place."

During our conversation Marge passionately recounted the vast number of taskforces, projects and initiatives that she has played an active role in. Many of these worked for a while, and then funding dried up or situations otherwise changed. Marge's daughter currently finds herself in a supported housing situation that is working for her and her family. Marge is, however, mindful of how quickly this situation could change. She notes "the one thing families have to remember if they get a solution today, that in most cases that's not a permanent solution." After thinking for a minute, she softened this thought and said:

> But then if we look at it as normal, our other family members, they don't just leave home and just the first choice they make, that's it for their life. So why do we expect that it's going to be the same for our kids who are disabled. So we have to expect we're always struggling for solutions because we have to.

I suspect her incentive to continue to search for solutions is why Marge continues to play such a strong and active role as an advocate for individuals with intellectual disabilities. Pointedly, Marge ended our interview by saying of my research, "So if you find a solution you can tell families... I'm being funny..."

Chapter Conclusion

The overviews of my interviews with government and community representatives presented here are intended to add information and context to the experiences described by the participants. My intent in interviewing these representatives was to ensure that a variety of perspectives and opinions were included in this research. The following chapter will provide the reader with some insight into the phenomenological interviews that I conducted with study participants and present an overview of the individual participants and the conversations that I shared with them.

Chapter Seven: Summary of Participants' Narratives

This chapter is intended to provide the reader with some insight into the phenomenological interviews that I conducted with study participants. Before providing the composite analysis in the next chapter, I am affording an overview of the individual participants and the conversations that I shared with them. I believe their individual narratives are powerful and provide an understanding of the reality of the struggles they face. The situations they describe highlight the state of disability policy in Canada. As detailed in an earlier chapter on policy and legislation, Bond and McColl (2013) analyzed Canadian disability policy and noted that disability policy in Canada is perceived as extremely complex and difficult to navigate. In 2017, McColl et al. continued this theme by describing disability policy as “a patchwork of legislation, regulations, programs, providers and entitlements that requires considerable probing to reveal, and considerable patience to understand” (McColl et al, 2017, p. 7 citing Boyce et al, 2001, Prince, 2004, Cameron and Valentine, 2001). Various other researchers have described Canadian disability policy as “conflicting, fragmented, incoherent, not user-friendly, a “hit-and-miss” affair” (McColl et al, 2017, p. 7). These academic assessments align with the actual life experiences described by the participants in this study.

While I am sharing general demographic information and details and quotes from our conversations, the individual identities of the participants remain protected. All participants signed consents and were aware that the conversations I conducted with them were being recorded and would be used for this research. All participants were made aware that they could request to view transcripts of our conversations but, to date, none have requested this access.

Summary of Participants

The results of this phenomenological study were developed using data collected from five face-to-face interviews with five family members of adult children with intellectual disabilities who had recently finished high school. I recruited participants by posting physical and digital copies of my recruitment poster at two organizations that provide services and support to individuals with intellectual disabilities and their families. The use of snowball sampling allowed participants to identify other potential participants in their social networks. Strategically, I only included participants who were immediate family members of adult children with intellectual disabilities who had graduated, or aged out of high school in Ontario, within the last five years.

Ultimately, the sample analyzed in this research is comprised of five parents; three mothers and two fathers. As previously noted, people with intellectual disability have varying degrees of impairment which are typically classified as mild (IQ 69-52), moderate (IQ 51-36), severe (IQ 35-20), or profound (IQ 19 or below) (American Psychiatric Association, 2018). Three of the parents who participated in this study reported having a child with a severe intellectual disability, one parent reported that his child had a moderate intellectual disability and one parent reported that her child had a mild intellectual disability. Four of the participants had a spouse while only one did not. Three participants had two or more children while two participants had only one child. Participant demographics are depicted in table 4.

Although this sample is comprised of individuals that represent a mix of social and economic situations, it could be argued that it comprises a homogeneous group of relatively well off, white participants. Further, this sample is only representative of the parental experience as no siblings were interviewed. Nonetheless, I believe that this sample is adequate to form the foundation of a phenomenological study of the transition that takes place in the families of children with intellectual disabilities when they age out of the school system.

Table 4

Participant Demographic Data

Participant	Sex	Marital Status	Number of Children	Adult Child's Category of Impairment	Adult Child's Age	Adult Childs Sex
Brenda	Female	Married	1	Severe	24	Male
Robert	Male	Married	1	Severe	24	Male
Maggie	Female	Married	2	Severe	25	Female
Sandra	Female	Single	3	Mild	22	Female
David	Male	Married	2	Moderate	26	Male

Participant Narratives

Qualitative inquiry practices afforded me the opportunity to engage with the parents of children with intellectual disabilities as I investigated the phenomenon surrounding how they experience and understand the transition that took place when their children aged out of high school. The following participant descriptions are intended to help the reader feel the essence of their lived realities as they endeavor to access post high school services and supports for their adult children with developmental disabilities.

As described in my methodology, phenomenological interviews typically consist of a series of open-ended questions that allow the researcher to explore, illuminate and probe participants' descriptions without limiting their ability to tell their stories (Chan et al., 2003; Flood, 2010). Given this, I followed an interview guide (Appendix E) rather than an interview script and the majority of my interview questions emerged from the cues of the participants.

Although I had not set out to do so, the individual conversations that I had with my participants led me to pose the same two questions to each person:

1. Do you have any advice to offer a similar family with a child who is on the cusp of aging out of the school system?
2. Do you think that the government could/should do anything to better address your child's needs?

Their responses to these questions are included in each participant description and are offered as a representation of their voice. Participant names have been changed to ensure that their identities remain confidential. Pseudonyms have been provided to help readers conjure a more complete picture of the participants through their narratives.

Narrative 1.

Brenda is the mother of an adult son with a severe intellectual disability and a differential diagnosis of severe autism. She is well spoken and well educated, holding a Master's degree in Social Justice and Community Engagement. Brenda and her husband are financially secure. She had the means and the foresight to begin preparing early for the day when her son would age out of the school system. Brenda noted:

> We attended an event called *Beyond Graduation* that Citizen Advocacy organizes every year. It was maybe a year or so before he graduated - to prepare ourselves as to what to do next. So we were quite aware as to what we needed to do.

Despite her early preparation, her family has not enjoyed a smooth transition to post-school life for their son. After struggling to secure funding and find appropriate day services for her son, Brenda left the work force to become an informal caregiver when her son aged out of high school three years ago. Although she loves her son deeply, Brenda feels cheated by the system. She stated:

> I did my master's degree in fundraising […] and then he graduates from high school and that's the end of that. So, what I'm saying is that the investment that I made in myself, and what the society put into me, and then for what?

Brenda is mindful of her situation and believes she has more financial security and a stronger ability to understand how to navigate the system than some other parents might have. She expresses concern for families who do not have the same means or knowledge about navigating the system. She is a vocal advocate for the rights of individuals with intellectual disabilities and spent five years on the Board of Directors for a local advocacy group. Brenda feels overlooked and willfully ignored by the government and contends that "politicians think that our families don't matter [because] our kids don't vote." Brenda, however, believes she knows how to work the system and told me that she became her son's legal guardian largely to afford him the right to cast a ballot.

Brenda had a bad experience in an IPRC meeting and opted not to attend her son's IEP transition planning meetings. She did, however, meet regularly with his teachers before and after each meeting and stayed well informed. She feels, however, that his transition planning set the bar too high for her son's abilities. She believes that the work placement goals that were set for her son were for much "higher functioning" individuals.

I asked Brenda if, after going through the transition herself, she had any advice to give to a family with a child who was on the cusp of aging out of the school system. She responded, "well, I would say start preparing early, start building your networks early and the kind of networks, meaning parents who have done it before, ahead of you, that can provide you with advice." I also asked Brenda if she thought the government could do anything to better address the needs of her son and those in similar situations, Brenda passionately replied:

> I think funding should be a human right. My son's diagnosis of autism is not going to change once he graduates from high school. He's still the same person, he's not going to all of a sudden have an IQ of a genius.

Narrative 2.

Robert is the father of an adult son with a severe intellectual disability and a differential diagnosis of severe autism. He has a successful career as a lawyer and is well spoken and matter-of-fact when discussing his son. Robert did not recall receiving any type of formal transition programming when his son was in high school, but he noted that his son's teachers would provide:

> You know, circulars pamphlets from organizations that want to help… So they would alert the parents. The teachers would say "oh you're about two years away from your son aging out, here's a pamphlet, maybe you should go this week." You know. Yeah. And we did.

Robert recalls that "just before aging out, [teachers] suggested looking at placements" for his son. He contends, however, that they were not able to suggest a work placement that could accommodate his son's high needs. He told me:

> They thought that he might be able to find a work environment where he would excel or something. And so they tried him in different places. That was the transition that they were focusing on that sort of missed the mark. Because in my estimation, I don't know, he can do a task for about a minute or two, not for nine

> hours. And he'd rather be doing a lot of other things, and the more you push, you get aggression issues, tantrum issues, all those things.

Despite the disconnect between Robert's son's abilities and potential work possibilities, Robert feels that the transition planning his son received "was all good intentioned." He expressed longing for the days when his son was eligible to receive services at school stating "his teachers were great, the assistants to the teachers were great. So he was lucky. I wish it could continue all his life, you know."

Robert voiced concern for families in more "dire circumstances" than his. He spoke specifically about the struggle faced by single and aging parents. Robert noted that he is lucky to have a wife who has taken on the responsibility of his son's full-time care, as they have not yet been able to access suitable day programing for their son. He is mindful of his wife's contribution to their family stating that, without her help, "maybe my job would be at risk, or my progression in my career would be at risk."

Robert conveyed frustration with the levels of bureaucracy that he feels he is forced to wade through in order to access the services that his son needs. He asserted:

> There's the Ministry of Children and Youth Services and then there's a Ministry of Community and Social Services. So while you're a child, I guess up to 18, one ministry is looking after your needs or diagnosis or whatever, and then it's like the bureaucracy doesn't talk to each other. He ages out of one ministry then another ministry starts again.[1]

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[1] Families are no longer required to switch between ministries when their adult children with intellectual disabilities reach adulthood as, "in June 2018, the Ministry of Community and Social Services was merged with the Ministry of Children and Youth Services to become the Ministry of Children, Community and Social Services." (Ombudsman Ontario, 2019, para 3).

When I asked Robert what he thought the government could do to improve the services that they offer to adults with intellectual disabilities, he responded that:

> In an ideal world it would be wonderful if [the government] could figure out who was going to be aging out, what amount is required to address those needs as of the day that they graduate, and have that amount allocated or accessible to the special needs adult or the guardians or the parents the day that they graduate.

Robert had the following advice for a family with a child who was on the verge of aging out of high school:

> So advice in terms of enjoying a couple of years before aging out. Figure out what the child is going to be doing. Who is going to be caring for the child, and where income is going to be coming from…whether you're able to hold your job if you have one…. or what type of job you would be able to hold down.

Narrative 3.

Maggie is a married mother of two children, a typically developed adult son and an adult daughter with a severe intellectual disability. She is middle class, a passionate advocate, and speaks openly and bluntly about the struggles that her family has endured. Maggie retired early from her job to become her daughter's full-time informal caregiver. She expressed frustration when she spoke of the transition that her daughter went through after aging out of the school system. Noting that she has not yet been able to access support dollars, Maggie said:

> Missed milestones, crisis after crisis, no resolution. If one more person asks me to do another plan… I'm at that point for our daughter. Don't fucking ask me to do one more plan, give me some supports. You can't implement a friggin plan and they all know it.

While Maggie laments the number of plans that were created, she could not recall any specific transition planning that was ultimately implemented for her daughter. Although she expressed gratitude for her daughter's teachers, she believes that they are ill informed about the realities of life after school for young adults like her daughter. She stated:

> And so teachers have their own information about what's going on. They're with kids who are coming out and teachers really don't know what's going on after. I don't mean that they don't know, you can say whatever you want and you can chart things and tell parents 'this kid should do this' and it's all bullshit. Nothing happens when they come out. The parents are out there on their own struggling, maybe having to quit their job. The system is disjointed.

Maggie is an active member of the disability community and a passionate advocate for the rights of individuals with intellectual disabilities. Maggie expressed concern for parents who are less able to navigate the system than her. She noted that she "always had a sense of how to navigate the system" and that she felt "a responsibility to pass it down." Speaking of her involvement in an organization that aims to support the families of individuals with intellectual disabilities, Maggie stated that "you can't blame families, a mother home with two disabled kids, a single mom and no money, and how is she going to figure all of this out?"

Maggie is obviously frustrated with the government and is openly critical of its policies. During our conversation she regularly pointed out the failures and inefficiencies she has experienced in the system. She tells me that she "can have a mansion for [her] daughter, but if [she] can't access support workers it doesn't matter." Maggie believes that funding should be streamlined and given directly to families. She emphasized this by stating:

> I don't care how many levels of bureaucracy you put in, that's wasting money. Give it to people for support. Give them some support dollars and let them decide. Don't bullshit us with service coordination.

Maggie gave me the copy of *Welcome to Holland* that is included at the beginning of this dissertation and told me:

> I've shared that so many times with families, I always have copies to give them, but it is true. Families are not only dealing with this whole medical crisis, school crises, housing crisis - it's a chronic grief. It's grief. You can't get away from that grief. First you have to…it's impossible not to have grief at the loss of a normal baby, then you have grief because you can't get them into the school system …you can't get them into... everything is overwhelming. Then you're a senior and you don't have any support and what's going to happen to them when you're gone?

When I asked her if she had any advice to give to a similar family on the verge of losing high school services, Maggie told me: "Families are powerless. What should they do? You create something and pray it works." As for the government, Maggie believes that they should enact laws that ensure that individuals have access to adequate developmental services. She opined:

> When our kids are out of high school no one is coming in with a solution for you. When you're in a legislated system, like the education system, they have to help and they have to find ways. But after that, no one owes anything to the families or there is nothing left. We have to have it legislated. That's the number one thing when you ask me. They need developmental services to be legislated.

Narrative 4.

Sandra is a single mother of three children. She has three adult daughters, one with a mild intellectual disability and two who are typically developed. Sandra makes a modest income at her retail job with a big-box retailer. She is forthcoming and speaks about all her daughters with pride. Sandra told me that she "had a difficult delivery" with her daughter with intellectual disabilities and that her daughter was "seconds away from having cerebral palsy." Nonetheless, Sandra's daughter has the mildest disability of all the participants profiled here.

Sandra told me that her daughter attended a special needs class at a high school where she says "she received a certificate of completion, not a diploma" when she turned 18. Other than guiding her towards a high school certificate, Sandra does not recall any significant transition planning that happened for her daughter at school. She tells me, however, that the high school guidance counsellor recommended that her daughter apply for a work-readiness program run by the local school board. Sandra says that her daughter was reluctant to participate in this program. She recounts:

> She didn't really want to go to [the program] because she assumed that when she finished [high school] that she'd be done. So, she was like, my friends are all graduating so why am I going to another school? […] I'm graduating, so I don't need to go to school anymore. I was like this is kinda like your college that you're going to go on to do. I said try it. That's all you can do. Try it and we will talk.

Sandra reports that she is satisfied with her daughter's transition from high school to adult life. When asked, she attributes this satisfaction to her daughter's acceptance and participation in the two-year work-readiness program that ended when she turned 21. During our conversation, Sandra told me that the teacher and EA who ran the program "would do life skills, job skills, personal skills, social skills." She says that they also "would arrange time outside of [the program] to meet together to go the movies or go to dinner." Today, Sandra's daughter continues to maintain the friendships and the part time job that she acquired during this program.

I asked Sandra if her daughter receives any government supports. She told me that her daughter started collecting income support from the Ontario Disability Support Program when she turned 18. I asked Sandra if the school helped her to access this, or any other, government service and she told me that it was all on her "own initiative."

While Sandra is happy with her daughter's current situation, she was more discouraged when I asked her about her long-term goals for her daughter. Sandra knows that she cannot care for her daughter forever but does not believe her daughter has the ability to live independently without support. Speaking of a supportive housing arrangement, Sandra stated:

> I'm hoping to do that. Really hoping. Or if not, get some kind of organization to do it. There again, they look for people with higher needs – I don't think she could live independently, totally independently. You know she's one that if the food's not in the house, she wouldn't go get it kind of thing. I think she would need assistance in the financial part to make sure that the rent was paid and that kind of stuff.

The advice that Sandra would give to a parent in a similar situation is hard to differentiate from how she feels the government could better address the needs of her daughter and those in similar situations. Sandra believes that more young adults should be given the opportunity to participate in programs like the one her daughter benefitted from, and strongly recommends it to parents. She asserted:

> Those kids were chosen for that program; it's not given to everybody. It should be given to more. I'm keeping my fingers crossed for other kids that they get to experience something like [it].

Facing increasing financial deficits, this very program that Sandra credits with much of her daughter's success is currently in jeopardy of closing its doors. While Sandra's transition story is more positive than the others presented here, I couldn't help but feel that her eagerness to participate in this research was a thinly veiled advocacy effort to keep the program running.

Narrative 5.

David is a married father with two adult children. While his daughter is neuro-typical, he describes his son as having a moderate intellectual disability and "classic autism" and tells me that he "was never in a regular class" at school. David and his wife are both civil servants and bring in good salaries. David is well spoken and articulate. The love and pride he feels for his son was evident throughout our conversation.

David told me that his son aged out of high school five years ago. He explained that he and his wife "put a lot of effort into" planning for this transition. David told me that his wife "called it knowing we are going to go off the cliff" and said that "planning had been long term [and] wasn't something [they] started a day or two before." Throughout our conversation, David frequently made reference to his efforts to have his son learn viable job skills. He told me that, leading up to his son's last year of high school, "there were meetings […] with the school and different people within the social service systems."

David said that during these meeting he pushed for the school to find work placements for his son. He recalled, "we said, we really want our son to develop job skills. So, to their credit, the school started finding more placements." While his son had some successful and some unsuccessful job placements, David credits the school with providing "bus training and someone to be there while he did his job to help him." On top of this, David told me about how he and his wife "invested" in job skills and detailed the years he spent teaching his son to deliver a local flyer independently. These efforts seem to have paid off as David's son currently holds down two part-time jobs doing repetitive kitchen prep work at two local restaurants.

David is satisfied with his son's transition out of high school. He believes that his son "is one of the only one's of his cohort who is not living in care right now." While this is true, his son does receive care and support from his roommate, a long-standing caregiver turned friend. While David is pleased with this arrangement, he is all too aware of the fact that this may not be a forever solution. He postulates that although he doesn't "want to tie her down to her brother for the rest of her life" his daughter may one day take on the responsibility of her brother's care.

It was evident during our conversation that David is less satisfied with the help and support that his son has received from the government. He bluntly told me that he finds Service Coordination to be "incredibly inefficient and ineffective as an organization." He complained of a lack of transparency in the organization and asserts that the case workers are "unskilled people that just make shit up and, you know, 9 out of 10 families just take it." David, however, is not one of these people and tells me of his successes complaining to his MPP. David considers many of these successes to be "buy offs." He asserts that, during the Ombudsman's 2015 investigation, "if you complained you got more funding and if you didn't complain you got to read the report in the paper." He told me:

> The day before the Ombudsman's report came out - we know a few families that wrote to express their concerns - we all got a phone call […] to say we'd been re-assessed and they were throwing money at us. So I think that's part of the reason

> why I was a little concerned about confidentiality, because I feel we got bought off. I feel that’s why we went from the $8,500 that we've gotten for 15 years to $32,000 approximately.

Although he is not proud of this, David told me that he would advise a parent in a similar situation “to lobby and complain to get more." He asserts that “this is not fair to anyone” and tells me that he would like the province to “have some courage and put in some real assessment tools to decide what people really need as opposed to the biggest factor, in terms of which funding you get, being related to how much you lobby.”

Chapter Conclusion

The preceding family participant narratives are intended to help the reader develop a sense of their varied stories and understand their individual challenges and joint commonalities. The core themes that emerged from their experiences will be discussed in detail in the next chapter and positioned in context with Schlossberg’s transition theory. Ultimately, these narratives offer a composite analysis of the transition from high school to the next stage of life for young adults with intellectual disabilities, as articulated by their parents.

Chapter Eight: Findings

This study explored how the families of individuals with intellectual disabilities experience the transition that takes place when their child ages out of the school system. A lack of previous Canadian research and literature pertaining to this experience compelled my interest in investigating this phenomenon. My analysis of recent media coverage of the needs of adults with intellectual disabilities, coupled with my examination of current and historical disability policies and legislation, reveals the multifaceted nature of this transition. Building on these two components of my research is the phenomenological interviews that I undertook with the parents of adult children with intellectual disabilities who have recently aged out of high school. While the previous chapter provided a portrayal of my individual participants and my discussions with them, this chapter provides a composite description that relates specifically to my research questions.

A qualitative framework was used to design this component of my research and methods common to interpretive phenomenology guided my data collection and analysis. Describing phenomena and their essences is a common goal of phenomenological research. Dahlberg (2009) contends that the essence of a phenomena "could be understood as a structure of essential meanings that explicates a phenomenon of interest" (p. 11). Viewed in this way, essence can be seen to comprise the essential characteristics of a phenomenon. As this is a primary goal of phenomenological research, this chapter strives to provide the essence, or a comprehensive portrayal, of how parents experience and understand the transition that takes place when their adult children with intellectual disabilities age out of school. As I do not want to dilute this essence with analysis, I will present these findings in context with the literature in the next chapter.

To ascertain how the parents who participated in this research understand and experience this period of transition, I relied on one primary and three secondary research questions, as follows:

Primary research questions.

1. How do the families of adult children with intellectual disabilities understand and experience the transition that takes place when their children age out of high school?

Secondary research questions.

1. How do the families of adult children with intellectual disabilities understand and experience the school based IEP transition process?
2. How do the transition variables outlined in Schlossberg's Four Ss model (situation, self, support, and strategies) affect the way a family experiences the transition that takes place when their adult children with intellectual disabilities age out of high school?
3. How do families experience disability legislation and policy in Canada and Ontario as their adult children with intellectual disabilities age out of high school?

This chapter presents findings that developed from data collected through transcribed participant interviews conducted with a total sample of five family members of adult children with intellectual disabilities who had recently aged out of high school eligibility in Ontario. As I was only able to interview parents, the results presented here are a culmination of parental voices and provide a deep perspective into the essence of their lived experiences. My interview guide provided a venue for rich depiction of how family members understood and experienced this transition. As suggested by Ray (1994), the majority of the interview questions that I asked in this study were not predetermined and, instead, followed the cues of the participants. Utilizing a more fluid interview guide allowed me to ask broad open-ended questions that did not lead participants toward particular answers.

I followed Amedeo Giorgi's four step method, described in detail in the following section, in the analysis of my transcribed interviews. To this end, I read each transcript multiple times while consciously engaging in bracketing in order to put aside my previous experiences, beliefs, and biases. From there, I identified meaning units which highlight the participants' experiences, beliefs and perceptions in relation to the transitioning of their children with intellectual disabilities from school to post-school life. This was accomplished by noting patterns in the way participants described experiencing and understanding their child's transition out of high school. I then clustered the meaning units to support the formation of themes. Ultimately, 11 coded themes developed from the meaning units. Finally, I applied Schlossberg's 4 Ss model (Schlossberg's, 2008) to the 11 coded themes. This allowed me to examine how the coping resources of Situation, Self, Support and Strategies influenced family experiences relative to the transition to post-school life for their adult children with intellectual disabilities.

Developing Themes

The analysis of interview data is not a completely straightforward undertaking as it does not lend itself to clear and concise operational procedures (Berg and Lune, 2012). Accordingly, researchers must rely on frameworks rather than specific, rigid guides. To this end, I employed Amedeo Giorgi's four step method in my efforts to identify patterns, themes, and meanings from my interview data.

Before a researcher embarks on a phenomenological analysis, it is expected that they use bracketing to suspend any preconceived notions they may have. In so doing, researchers are able to put aside their previous experiences, personal beliefs, and biases which enables them to better represent the experiences of their participants. To do this, I followed the bracketing strategies outlined by Chan et al. (2003), which are discussed in detail in Chapter 3, by delaying the bulk of my literature review until after I completed the first draft of my data analysis, developing a broad, open ended interview guide, and carefully considering and ultimately choosing to couch my analysis in interpretive phenomenology. Further, I was careful to acknowledge my connection to this research as identified in the autobiographical statement presented in Chapter 1 and made a conscious and deliberate effort to recognize and set aside my predispositions during my data analysis.

The first step in Giorgi's method asks researchers to familiarize themselves with their data. To do this, I read and reread each transcribed protocol interview over several weeks. In so doing, I was able to develop a sense of each transcript's whole and better understand its meaning from the standpoint of each participant (DeCastro, 2003). During this first step, I was careful to focus on the intentionality of the participants and resisted the urge to make any initial interpretations of their experiences.

After becoming familiar with each protocol, Giorgi instructs the researcher to begin the task of identifying meaning units. DeCastro (2003) contends that the goal in this step is to separate the text into units or blocks that express a self-contained meaning. To do this, I followed Giorgi's advice and looked for changes in topics, meanings and descriptions in each of my interview transcripts. During this process, I made a conscious effort to look at, and understand, each of these units in terms of the transcript's meaning as a whole. To this end, I repeatedly reviewed the units within the context of the participant's complete transcript which helped me to ensure that the developing units aligned with the participant's intentions. Careful note-taking during this step helped me to make sense of the meaning units and directed my focus during this stage of inquiry. Through this process, I identified 276 statements, or meaning units, as significant to this study.

Giorgi’s third step requires researchers to probe their identified meaning units for their dominant meaning in relation to the context of the study and re-describe them using academic language. This process had me fully immersed in the data, identifying and clustering concepts, seeking input from others, revisiting the data, revising and re-clustering concepts and then re-bracketing and repeating the process several times to ensure authenticity. Ultimately, 11 coded themes developed from this effort and include: Ineffective Government Services; Advocacy; Funding; Support Networks; Parental Capacity; Short Term Preparedness; Long Term Planning; Waitlists; Self-Sacrifice; Government Apathy; and Disability Legislation (Table 5).

Table 5

Coded Theme Response Frequency

		Participants					
		N1	N2	N3	N4	N5	Totals
Coded Themes	Ineffective Government Services	13	11	10	2	19	56
	Advocacy	7	6	13	3	16	45
	Funding	5	3	13	1	7	29
	Support Networks	4	3	7	6	5	25
	Parental Capacity	3	4	9	0	9	25
	Short Term Preparedness	3	6	5	5	5	24
	Long Term Planning	5	3	7	2	6	15
	Waitlists	3	4	3	1	3	13
	Self-Sacrifice	5	3	3	0	2	13
	Government Apathy	4	4	3	0	1	12
	Disability Legislation	2	2	3	2	2	11

The last step in Giorgi’s four step method requires the researcher to make a general description of the phenomenon under study which integrates and synthesizes the transformed meaning units and describes what all the transcripts have in common (DeCastro, 2003).

However, as this study is also couched in Schlossberg’s theory of coping resources, I endeavored to ascertain how these variables are entwined in the collective experience of this phenomena before completing this final step. To do this, I carefully aligned the 11 coded themes that emerged from my data analysis according to four variables, or coping resources, in Schlossberg’s 4 Ss model; Situation, Self, Support, and Strategies (Schlossberg’s, 2008). This allowed me to examine how these factors contribute to the shared experience of the transition from school to post-school life for the parent of adult children with intellectual disabilities in Ontario and represent the core themes derived from my analysis (Table 6).

At this point, I re-immersed myself in Schlossberg’s theory by reviewing the literature that pertains to her Coping Resources theory (Schlossberg’s, 2008). I spent several weeks reacquainting myself with Schlossberg’s overall theory of transition and focused specifically on the four major factors that she purports to influence a person’s ability to cope with a given transition. To do this, I read and reread Schlossberg’s work to ensure that I fully grasped and understood each of the four variables. Additionally, I explored a variety of studies that successfully employed her theory to gain insight into its application. Once I was fully comfortable with my understanding of Schlossberg’s Coping Resource theory, I began the task of aligning my 11 coded themes with these four variables. During this process, I continually revised my categorizations as I revisited the literature to ensure that my delineations held true to Schlossberg’s intended divisions. I sought advice and feedback from others and reviewed my initial meaning units to ensure that my groupings aligned with the participants’ intended meanings. It was at this time that the validity of my bracketing techniques was verified as I, no doubt, would have coded differently had I been thinking about the application of Schlossberg’s theory during the development of my coded themes. The results of this effort are presented in Table 6 and discussed in detail in the next section.

Table 6

Coded Themes Aligned with Schlossberg's 4 Ss

Schlossberg's 4 Ss	Coded Themes
Situation:	Short Term Preparedness
	Waitlists
Self:	Parental Capacity
	Funding
Support:	Support Networks
	Ineffective Government Services
Strategies:	Modify the Situation:
	Advocacy
	Disability Rights
	Self-Sacrifice
	Control the Meaning of the Situation:
	Government Apathy
	Manage Stress:
	Long Term Planning

Coded Themes and Coping Resources

Schlossberg identified the variables of Situation, Self, Strategies, and Support as the key factors that influence an individual's ability to cope with a given transition. She contends that a person's effectiveness in coping with transition depends on their resources in these areas. The following sections will review each of these four areas and explain how they connect to the coded themes identified in this study.

Situation.

The Situation variable refers to the type of transition (expected or unexpected), the context in which the transition occurs, and the impact of the transition on the individual's life. Factors such as timing, control, role change, duration, previous experiences, or concurrent stressors are considered here as they can lead an individual to appraise the impact of a transition differently.

Aging out of school eligibility is an expected transition for all adults with intellectual disabilities and coincides with the year they turn 21. Parents do not have significant control over this process but can assert some control by preparing for the event. This short term preparedness is, however, hampered by long waitlists to access services in Ontario. As such, I deemed the coded themes Short Term Preparedness and Waitlists as directly relevant to this variable.

The Short Term Preparedness theme relates to how parents prepared for their child's immediate needs upon aging out of high school. It encompasses awareness, IEP planning, job skills training, funding and service applications, knowledge seeking and role change arrangements. The Waitlist theme encompasses the services, programs and funding that parents struggle to access in Ontario.

Self.

The Self variable refers to personal and demographic characteristics (age, gender, race, health, socioeconomic status) which impact an individual's perception of a transition. In addition, the Self variable also encompasses the psychological resources (ego, outlook, self-efficacy) which a person has at their disposal. While I did account for basic demographic variables in my participant profiles, I did not account for them when I coded my central themes. As such, I do not have a theme that is directly relevant to demographic characteristics.

Nonetheless, it is important to consider that all of my participants fit a similar demographic in that they are all white, middle aged and relatively well off. In addition, I determined that the Funding theme is relevant here as it is directly correlates with socioeconomic status. This theme encompasses meaning units that relate to the funding that parents have applied for and/or received as well as the services that this funding covers and those that it does not.

An individual's psychological resources are typically thought of in terms of a person's mental and emotional state. The Self variable links these states with individual attitudes toward given transitions. During my research, I did not attempt to evaluate the mental or emotional state of my participants. While I would say that they were overwhelmingly frustrated, I did not engage in emotion coding during my analysis. I did, however, identify meaning units that related to Parental Capacity to negotiate bureaucratic systems and advocate for their children. As such, I ascertained that this theme was relevant here.

Support.

The Support variable refers to the help available to individuals at the time of transition. Supports may include intimate relationships, family units, networks of friends or institutions and communities. The coded theme, Support Networks, fit easily into this category as it includes meaning units related to the family, community and institutional supports that parents received and participated in.

The federal and provincial governments provide a variety of services and supports for adults with intellectual disabilities. However, the meaning units that surrounded these services and supports focused exclusively on their perceived inefficiencies such as a lack of communication, arbitrariness, confusing nature, inaccessibility, incompetency, and inadequacy. As such, this theme was coded as Ineffective Government Services and represents the most prevalent meaning unit identified. Despite their perceived shortcomings, these governmental services are directly applicable to the support variable.

Strategies.

The Strategies variable refers to the coping strategies that individuals use to prevent, alleviate, or respond to stress. This variable is broken down into three succinct parts; (a) strategies that modify the situation, (b) strategies that control the meaning of the situation, and (c) strategies that manage stress. As such, I aligned my themes with each of these three parts specifically.

I associated strategies that modify the situation with those coded themes that involved action taking. The theme of Advocacy was an easy fit here as it includes all meaning units that relate to the ways in which parents describe standing up for the rights and best interests of their adult children. The Self-Sacrifice theme is also relevant here as it represents the myriad of ways that parents described putting their child's interests and needs in front of their own. This is due to the fact that parents are better able to shape and modify their child's transition when their own needs are minimized. Lastly, parents focus on Disability Rights, which encompasses meaning units surrounding current disability rights and legislation in Canada and Ontario as well as those things which parents feel should be legislated and protected as rights.

I categorized the theme Government Apathy as a strategy that parents use to control the meaning of the situation. This theme represents meaning units in which participants indicated that the government doesn't care about their children with intellectual disabilities. I ascertained that this theme allowed participants to control the meaning of their transition as it justified the problems and barriers that they faced.

Finally, I determined that the Long Term Planning theme could be seen as a strategy directly linked to the management of stress as this type of planning often reduces anxiety. This theme is comprised of the meaning units in which participants expressed their long term goals, emergency and contingency plans, and questions about the provision of care for their children after their death.

Cohesive Description of the Experience of Transition

Schlossberg argues that individual responses to transitional events depend on the interaction and balance between the four coping strategies of Situation, Self, Support, and Strategies (Schlossberg's, 2008). This means that similar transitions have the potential to be perceived and experienced in different ways. Phenomenology, on the other hand, strives to emphasize the meaning of an experience for a number of individuals. To this end, I endeavored to identify similarities in participant experience and brought these together to form my 11 coded themes. These themes were then linked to Schlossberg's four Coping Resources (4 Ss) to create a comprehensive portrayal of how parents experience and understand the transition that takes place when their adult children with intellectual disabilities age out of school.

Cohesive description: Situation.

The parents of adult children with intellectual disabilities expect and prepare for the transition that takes place when their children age out of school eligibility the year they turn 21. As this is a legally mandated age cap, parents have no control over this timeline. They do, however, assert some control over this transition by preparing for it in advance. David captured this theme when he observed that he and his wife put a lot of effort into preparing for the loss of high school services. He stated:

> My wife called it, like, knowing we are going to go off the cliff. We put a lot of effort into, you know… like it wasn't something we started preparing for a day or two before.

Likewise, Robert echoed David's sentiment when he articulated the long list of things that parents should prepare for. He detailed that parents need to:

> Figure out what the child is going to be doing. Who is going to be caring for the child? And where income is going to be coming from, and whether you're able to hold your job if you have one. Or what type of job would you be able to hold down around the time when you might have a temporary solution. Or, a solution on certain days, for your special needs adult child.

Parents plan for the transition that takes place when their adult children with intellectual disabilities age out of high school in many similar ways. They participate, to varying degrees, in the IEP transition planning process and ask that their children learn applicable life and job skills. In Ontario, all exceptional students are entitled to a variety of publicly funded special education services and supports. At the cessation of high school, parents seek to replace these services without cutting into their bottom line. To do this, they must navigate the social service system to apply for government funded subsidies and services before the time that their children leave school.

Although they apply early, parents struggle to access the governmental services and funding that are potentially available to their children with intellectual disabilities. With a glut of applicants and limited resources, parents find themselves on numerous service waitlists. Robert summarized this experience when he told me about his wait for Passport Funding. He asserted:

> I think we qualified for it, but there was no money to allocate to those who had qualified. It's an objective qualification, we were qualified, just there wasn't enough money in the pot, and the pot was already spoken for by the people who had qualified decades earlier, years earlier, and who had an amount allocated according to the needs of themselves or their children. And so we were just on a waiting list, waiting for the government of the day to replenish the pot. And then start working down the list and so our son's name came up three years after he graduated.

Given the lack of immediate funding, parents are forced to negotiate new roles in their child's life as the custodial aspect of school is taken from them before they can access any or all of the governmental services and funding that they need and are entitled to. Speaking bluntly on the issue of waitlists, Maggie said:

> Every region has its own Developmental Services Office and you go through there for a major five hour, ten-hour assessment. And then there's still no funding. If your kid is assessed that yes he should have this and he should have that, that doesn't mean he's getting it. That means he's on a list somewhere with 17,000 other people.

She goes on to say that she "can have a mansion for [her] daughter, but if she can't access support workers, it doesn't matter." Brenda echoed Maggie's concern stating, that when it comes to housing, "you have to be dead or at the hospital before you get help." Accordingly, the way in which parents assess their situation at the time of transition is couched in their ability to plan for this transition which is, in turn, couched in their ability to access and replace lost services.

The waitlist situation and difficulties that the parents in this study describe are affirmed by the research detailed in my literature review. Noted in that chapter is the 22 year long wait list for community housing (Spagnuolo, 2016), the fact that the website of the Ministry of Children, Community and Social Services classifies ODSP as a program of last resort and advises individuals looking into ODSP to first explore financial viability through other options, and the growth of the waitlist for Passport Funding from 3700 in 2012 to 14,402 in 2015 (Dubé, p. 22). The personal experiences of the participants make the reality of these statistics heartbreakingly clear.

Cohesive description: Self.

Parents of children with intellectual disabilities span a vast array of personal and demographic characteristics. While these characteristics represent more differences than similarities, most parents seek to provide their children with the best supports and services despite their relative socioeconomic positions. Services and supports for children with intellectual disabilities are expensive. Parents balance this cost by applying for funding that is available through the government. Maggie compares access to government subsidies to "individual life support" and simply states that "most families cannot afford to pay, so they need to get the support dollars."

In order to access the services and supports that the government provides to adults with intellectual disabilities parents must navigate complicated and complex bureaucratic systems, fill out applications and provide supporting documentation. Speaking of the work that she puts into organizing her son's applications, Brenda stated:

> You know, my phrase to people who ask me how my life is, is “I don't even have time for an expresso.” And that should be quick. Like I am running around, doing this, this and this, you know?

Further, she went on to say:

> I find myself now, I'm like a manager of his affairs. Even with Passport funding, you have to get everyone to sign up, you have to submit them according to their rules, and work-fair has to come in and you have a subset of activities that you have to do.

Parents face a heavy work load managing services for their adult children with intellectual disabilities. They find this to be a time consuming and labour intensive process. David summarized this position when he asserted that parents need to develop the skills to navigate governmental red tape. He bluntly stated:

> My wife and I both worked for the government and she has the great line saying, we're civil servants they're civil servants - we will not be out administrated by these people. Like we know we know how this shit works because that's our job. We know how to do it.

Parents are cognizant of the amount of time and effort that goes into applying for and managing the governmental services that their family receives. David summarized this position when he said:

> When we get funding from the province, it is like running our own business. At the time, we were getting about eight thousand, and we were probably spending another ten. So about eighteen or twenty thousand a year we're spending on

> different things to support [our son]. And what I mean by a small business; it's employees, it's training people, firing sometimes, continual hiring.

Given the immense task of managing their children's care, parents worry about how others are coping with this load. Speaking of her capacity to navigate the system, Brenda opined: "I'm managing this and I'm thinking, what happens in cases where the parents don't have the same skills, and are not so organized?" Likewise, Maggie questioned:

> So how does a poor person who has no... I feel lucky in that, it was easy for me to navigate and to figure out the system, and figure out where... How would a person who doesn't have the experience and is intimidated because everyone else knows more than them? That's what gets me.

Statistics Canada data indicates that Canadians who care for their children with intellectual disabilities report high levels of psychological and financial difficulties resulting from their responsibilities (Turcotte, 2013). The above discussion on accessing government funding provides insight into some of the factors driving the psychological and financial difficulties that the participants of this study acknowledge. Considering the comments of the parent participants, it can be concluded that the governmental funding and services that parents receive, in conjunction with their ability to navigate bureaucratic systems, directly affects the way in which they experience this time of transition.

Cohesive description: Support.

The parents of adult children with intellectual disabilities rely heavily on support networks to navigate the transition that occurs when their child ages out of school eligibility. During the transition process, parents turn to other parents for this support. Brenda articulated that joining a group for parents in similar situations:

> …was an opportunity for us to learn from other parents. The kind of stuff that you don't get to hear from the Ministry, from Service Coordination, you get to hear from pioneers. And they say, how do you know a pioneer? By the arrows in his back. So you hear from other parents in terms of where it went wrong. Where you should go, and where you shouldn't go, and what strategies to use. It's the parents that I've learned a lot from as to what to do.

Maggie took this a step further and asserted that progress for one is progress for all. She stated that "every single thing that's done, every single thing that people are doing, is helping someone else." She summarized this standpoint by stating that "when families are connected to each other, they access more information and become more empowered."

As Brenda explained, parents rely on other parents to pass down their experiences. This is particularly the case for information regarding the accessing of governmental supports. Parents are forced to contend with significant misinformation, complicated processes, and general ineffectiveness when they try to access governmental supports for their children. Service Coordination, the gateway to Passport funding, is particularly troublesome. Brenda asserted that the Needs Assessment[2] that Service Coordination conducted for her son was inadequate. She states that "they did an assessment of his needs and […] recommended seven different places.

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[2] Developmental Services Ontario requires that applicants submit a completed application and Needs Assessment. This Needs Assessment is based on the Supports Intensity Scale (SIS) developed by the American Association of Intellectual and Developmental Disabilities (AAIDD). According to the AAIDD, the SIS is a standardized assessment tool that "measures the individual's support needs in personal, work-related, and social activities in order to identify and describe the types and intensity of the supports an individual requires" (AAIDD, 2019). The SIS must be administered by a professional working in the field of human services such as a case manager, psychologist, social worker (AAIDD, 2019).

And what do you know, he was rejected by all seven." Speaking of the same mandated Needs Assessment, David recalled:

> They had us do this test, which I found most of the question really not relevant for [our son]. He really just couldn't follow them. They spent one day doing it at the house with us. Questions like, tell us what are your dreams, what are your interests? And [our son] really didn't understand what they were saying and he went upstairs - he was obsessed with Scrabble words - and got a Scrabble dictionary and started reading words in the dictionary. He had no idea what she wanted.

David opined that front-line government workers "don't have the sophisticated skills, the capacity and capabilities to do their job effectively. So they create rules, create processes, but don't really understand what they're for." Maggie shared this view and offered:

> Don't bullshit us with Service Coordination. DSO they call it now. Now they just hired housing coordinators provincially for regions, so they'll help families - they'll help families do shit all because they got no power. They can't help them. I'm sorry to be so blunt.

As discussed in the literature review chapter, social supports, such as the support networks discussed above, have been correlated with lower level of stress (Dyson 1997; Feldman et al. 2002; Robinson, 2016; Smith et al. 2001), distress (Gallagher et al. 2008; Robinson, 2016) and marital problems (Dunn et al. 2001). That said, at least from the perspective of the participants in this study, the support that parents receive from community networks is tempered by the lack of support that they believe they are receiving from the government. As such, their experience with support networks during this time of transition is imbedded within their experiences with the government. It appears that they use the social networks partly as an information vehicle to assist with, and improve, their ability to access government services.

Cohesive description: Strategies.

The parents of adult children with intellectual disabilities have many strategies to lessen the stress that they experience as their child ages out of school eligibility. During this transition, parents attempt to modify their situation by advocating on behalf of their children and fighting for what they believe they are entitled to. Parents are “strong advocates” for their children and are proud of the work that they do to support them. In many ways, parents are their children’s only voice. They band together in an effort to make their voices louder and take on active and vocal roles during times of political change. David succinctly described the inherent value of this advocacy work when he asserted that the parents of children with intellectual disabilities are the “fiercest of parents.”

Parents frame their advocacy work in terms of unmet rights. They advocate for the enactment of new legislation and laws that would guarantee adequate services and support for their children. Summarizing this position, Maggie declared that families “need developmental services to be legislated,” while Brenda proclaimed that “housing for our kids is a human right.”

The advocacy work that parents engage in during the time of transition in order to support and improve their children’s lives post-school represents a significant sacrifice of their time. All told, parental efforts to smooth the transition process equate to a significant self-sacrifice of their time and financial resources. Speaking of this time commitment, Sandra stated, “we just can’t sit down and do nothing.” Further, Brenda offered:

> I'm talking to a father and the father starts snoring in the middle of the conversation because he was the one designated to be up all night giving

> medication [to his autistic son]. Now, I expect that father to go and advocate on top of his regular job? It's a lot to ask.

In addition to the sacrifice of their time, parents pay significant out of pocket costs for their children's care. Many parents finance homes for their children, pay for services and programming, cover costs while they sit on waitlists, and seek to provide the best services and opportunities available for their children. While the advocacy work and self-sacrifice that parents engage in may indeed adjust their situation it, no doubt, comes at a significant cost to their time and financial situation.

Parents described facing significant stress, anxiety and uncertainty when their children age out of eligibility for school-based programs. This is often a dark and frustrating time for parents as they seek to overcome barriers and obstacles in their efforts to replace lost services. To overcome these feeling, parents attempt to control the meaning of their situation by viewing the government as an enemy. Essentially, parents take the stance that the government is apathetic and does not care about the need of their vulnerable children. On this topic, Brenda succinctly stated that "politicians think that our families don't matter [and] are more interested in buying beer right now." Echoing this sentiment, Maggie more subtlety asserted: "When it's someone else's agenda, it's not about your life. It's not person centered. It's someone else's agenda." Summarizing this position, Robert stated that:

> Governments have a choice between buying guns and buying butter […] So it's choices. Political parties make choices. And they rank the choices, and what's happening in our society, because it's not a legislated requirement, is that the priority, which is to look after this segment of our population which is extremely vulnerable and their aging parents, doesn't make the list.

As discussed in an earlier chapter on policy, provincial governments bear most of the burden for providing disability supports. However, none of Canada's provinces are currently doing an adequate job of meeting the needs for these supports. As stated by Burns and Gordon (2010), a prominent theme exists in the Canadian literature that calls for federal disability legislation that is stronger, more cohesive across the country, and more effective than the existing Canadian Human Rights Act and Canadian Charter of Rights. New robust legislation is required to ensure that all provinces in Canada have appropriate services and programs available to protect and support persons with disabilities (Burns and Gordon, 2010). Given this assertion, it appears that parents who advocate for the enactment of new legislation and laws that would guarantee adequate services and support for their children are united with the academic community in this intent.

Finally, parents manage the stress and anxiety that they feel at the conclusion of their child's high school eligibility by planning for the future. They begin this long-term planning early, when they advocate for their children to learn relevant life, social and job skills while still at school. Aware that they will one day, inevitably, be unable to care for their children, parents seek to create security for their children when they are no longer able or around to provide it. Maggie clearly stated this worry when she offered "families can't be there forever to advocate" and that "there's no way we're leaving it to chance."

Chapter Conclusion

The application of Giorgio's model to my interviews with parents revealed eleven themes to which I applied Schlossberg's 4S model. Undertaking this analysis revealed an overall profile of the essence of the experience that parents of adult children with intellectual disabilities have when their children age out of school. These parents work to prepare for the end of services they know they will face when their children turn 21. However, despite this knowledge and preparation, when they try to access the services their adult children should be entitled to post-school, they face long wait lists, bureaucracy and a system that is difficult to navigate. They experience stress and significant financial burdens. To help themselves cope with these challenges, they turn to support networks, often as a tool to give voice to their frustrations and as a mechanism to help overcome the barriers they face in their attempts to access needed services. These barriers to services ultimately lead parents to conclude that have unmet needs and rights that should be rectified through legislation. They assert that the government is apathetic, ineffective, and just doesn't care. Nonetheless, they can't stop trying; they can't stop advocating; they can't stop hoping for change. They plan, they advocate, they despair, they rejoice at small victories and, through it all, they worry about their children's welfare and future.

In 1977, the term "hit or miss affair" was coined by Joan C. Brown when she studied disability policy in Canada. In 2004, Michael J. Prince re-examined Canada's disability policy and affirmed that the term was still applicable. As evidenced by the information provided in the chapter on policy and legislation, I contend that the term "hit or miss affair" is still an accurate description of the state of disability services and supports in Canada. The experiences of the parents of adult children with intellectual disabilities described above provide concrete evidence that, sadly, this term still truly and accurately does describe the challenges that individuals with disabilities and their families work daily to overcome.

The findings provided in this chapter will continue to be discussed in the next chapter where they will be presented in context with my literature review, policy analysis, and news article content analyses.

Chapter Nine: Discussion

The foremost aim of this study is inherent in my primary research question which asks how the families of adult children with intellectual disabilities understand and experience the transition that takes place when their children age out of high school. To frame this pursuit, I also asked three secondary questions: (a) How do the families of adult children with intellectual disabilities understand and experience the school based IEP transition process?; (b) How do the transition variables outlined in Schlossberg's 4 Ss model (situation, self, support, and strategies) affect the way families experiences the transition that takes place when their intellectually disabled adult children age out of high school?; and (c) How do families experience disability legislation and policy in Canada and Ontario as their adult children with intellectual disabilities age out of high school?

In order to achieve this goal, I turned to the families themselves and asked participants to recount their lived experiences during this important transition. Throughout my data collection and subsequent analysis, I relied on methods common to interpretative phenomenology to guide my process and ensure its viability. To this end, I utilized Amedeo Giorgi's five step method to identify meaning units which highlighted the participants' experiences, beliefs and perceptions in relation to the transitioning of their children with intellectual disabilities from school to post-school life. I then clustered the meaning units to support the formation of themes (Giorgi, 2009). Ultimately, eleven coded themes developed from this effort. Finally, I applied Schlossberg's 4 Ss model to the eleven coded themes (Schlossberg's, 2008). This allowed me to examine how the coping resources of Situation, Self, Support and Strategies influenced family experiences relative to the transition to post-school life for their adult children with intellectual disabilities. This chapter weaves these findings together with my literature review, policy analysis, and news article content analyses. Finally, I clearly relate these interwoven connections to my research questions.

Situation: Transition Planning, Policy and Access to Services

The Ontario Education Act mandates that all exceptional children be given access to appropriate special education programs and services without payment of fees (Education Act, 1990). These services, however, come to an abrupt end the year students turn 21 and age out of school eligibility. Along with the loss of these programs and services, exceptional students and their families also lose the custodial support provided by the school system. Mageou (2011) notes that the custodial function of schools is one of the most important responsibilities of public education in North America. She contends that, aside from education, schools provide physical guardianship of children, which allows their parents to work, and thereby functions as an irreplaceable aspect of our economy. As children grow and mature, the parents of typically developing children rely less and less on the custodial care provided by the education system. The parents of adult children with severe intellectual disabilities, however, must find a suitable replacement for this care when their children leave school.

As discussed in the introduction to this thesis, transition planning in Ontario schools is intended to help exceptional students make a successful transition from school to work, further education, or community living (Ontario Ministry of Education, 2002). The Ontario Ministry of Education regulates IEP transition planning and requires individuals, families, and relevant agencies be involved in the creation of student specific transition goals with clear actions and timelines for their attainment (Ontario Ministry of Education, 2000). This regulation facilitates a person centered transition planning model, which is seen by many as best practice, as it guarantees students and their families the right to take part in the planning process. This right was realized by all the parents who contributed to this study as they all, to some degree, participated in their child's IEP transition planning. However, it should be noted that the degree to which their adult children participated in this process was not addressed by this research.

I asked an Education Officer with the Ministry of Education how current transition planning practices are preparing exceptional young adults and their families for the transition from school to post school life. Although she conceded that it is not directly relevant to exceptional students, she pointed me to the Ministry's 2013 career development policy document *Creating Pathways to Success: An Education and Career/Life Planning Program for Ontario Schools* and noted that the overall vision of the policy outlined in this document is that:

> All students should leave secondary school with a clear sense of self and a plan for their initial postsecondary destination and with confidence in their ability to implement and revise or adapt their plan throughout their lives as they and the world around them change. This vision sees students as the architects of their own lives.

The person centered transition planning policy that is in place in 2019 in Ontario's public schools can be seen to meet this mandate as it affords exceptional young adults and their families with more opportunities to articulate their own wants and needs for the future. However, the articulation of these needs, and the drafting of a thorough transition plan, does not guarantee the existence or availability of services to meet them (Kaehne & Beyer, 2014). Person centered transition planning affords young people and their families with more opportunities to articulate their own wants and needs. Thus, an increase in person centered transition planning has the potential to create new service demands. Given that these service demands may differ from the current services being offered, Kaehne and Beyer (2014) postulate that service agencies may struggle to meet these newly articulated service requests. Claes et al. (2010) caution that the person centered planning model risks becoming a mere paper exercise if these plans are driven by service availability rather than service request. The authors note that planning around service availability alone fails to increase independence, choice or inclusion for transitioning youth. Planning around service request, however, is also problematic as even carefully crafted transition plans, built on the needs and desires of young people and their families, are little more than wasted effort if these young people later find themselves placed into available services that do not meet their original wants or needs (Clases et al., 2010; Kaenne & Beyer, 2014).

This service gap inherent in person centered planning is clearly articulated by Maggie. Speaking about planning in general, she asserted, “If one more person asks me to do another plan […] Don't fucking ask me to do one more plan, give me some supports. You can't implement a friggin plan and they all know it.” Maggie’s frustration is underscored by that fact that, to date, there are no published statistics or studies regarding the outcomes of Ontario’s IEP transition planning process. Given this, it is difficult to quantify the overall success of Ontario’s transition planning model. On their website, the Geneva Centre for Autism has a list of North American resource guides for parents facing transition planning challenges. This list identifies various Canadian and American transition planning guides and briefly summarizes them. Relative to the Ontario Ministry of Education’s document entitled *Transition Planning: A Resource Guide*, the description states: “Ah, the beautiful dream. What could, but probably never will, be done for transition planning through the school system” (Geneva Centre for Autism, 2018). So, while it may be difficult to quantify the outcomes of Ontario’s IEP transition planning process, the caustic summary provided by The Geneva Centre for Autism does evaluate Ontario’s transition process as good intentioned but falling short of the ability to meet those good intentions; an evaluation that is validated by the participants in this study.

The Education Officer from the Ontario Ministry of Education contends that the Ministry cannot pinpoint the biggest challenge facing exceptional young adults and their families at the cessation of high school as this is dependent on individual diagnoses and community variables. Nonetheless, Marge McCabe offered her anecdotal observations from her extensive work supporting families through the Families Matter Cooperative. Ms. McCabe believes that IEP transition plans come up short because families struggle to access the funding and services that are planned for. She believes strongly that support services for individuals with developmental disabilities should be a legislated right. Similarly, Senator Munson maintains that the government should not put restrictions on the funding and services that people with medically diagnosed conditions such as autism, or other developmental disabilities, receive. He passionately argues for a National Autism Strategy and contends that the federal and provincial governments must work together to support individuals in the disability community. Like Ms. McCabe, Senator Munson believes that the government is not doing enough to support young adults with intellectual disabilities after they age out of high school.

Despite their extensive knowledge and planning, the parents who took part in this research have come up against long wait lists, bureaucracy and a system that is difficult to navigate in their efforts to access adult services for their children. These barriers to services have ultimately led participants to conclude that, despite access to best practice transition planning practices, their adult children face unmet needs and rights after aging out of the school system, and that these unmet needs should be rectified through appropriate legislation. These parental conclusions align with the opinions voiced by Ms. Marge McCabe and Senator Jim Munson.

Self and Support: Services, Support Networks and Caregiver Burden

In theory, Ontario offers significant support vehicles that could be included in transition plans for young adults with intellectual disabilities as they age out of high school services. As individuals and families reach this milestone, however, the reality can be much different as they seek to replace the children's services that are no longer available to them. Many advocacy organizations advise parents to plan early and to be aware that they may need to use their own financial resources to help and care for their adult children with disabilities (Windsor-Essex, 2014; Families Matter Cooperative, 2014).

Applying early does not, however, guarantee families access to the governmental services and funding that are theoretically available to their children with intellectual disabilities. With a glut of applicants and limited resources, parents often find themselves on numerous service waitlists. The most recent available statistics find over 14,000 individuals with developmental disabilities sitting on separate waitlists for appropriate housing and passport funding (Spagnuolo, 2016; Dubé, 2016). The stories of long wait times for housing, day services and/or provincial funding faced by the families of adults with intellectual disabilities were the focus of roughly two thirds of the articles analyzed in this study. This media focus has the capacity to influence public opinion, understanding and perception, and the potential to incite political action (Wilson 1995; Boykoff & Rajan 2007; Jacobson, Langin, Carlton, & Kaid, 2012). To date, however, large scale political action has not been realized, leaving the families who took part in this research feeling overlooked and insignificant.

Half of the front page articles, and roughly one third of all of the articles analyzed in this study were prompted by a family's immediate need for help in caring for an adult child with an intellectual disability. Despite the immediacy of many families' needs, the Ministry of Community and Social Services classifies ODSP funding as a program of last resort and advises individuals to look for help from every other potential source before applying to ODSP to cover basic living expenses such as food and housing (Ontario Ministry of Children, Community and Social Services, 2018, ODSP). Further, Ontario allows publicly funded, privately operated group homes to set their own eligibility criteria for admitting residents and to evict residents with needs that are deemed to fall outside of their admissions criteria (Spagnuolo, 2016). In his 2016 Ombudsman's Report, Dubé asserts that this allowance has resulted in a "service gap for a core group of individuals who are traditionally difficult to place" (p. 120). Combined, ODSP's last resort policy, and provisions which afford publicly funded group homes the right to arbitrarily admit and evict residents, result in those who most need supportive housing services and financial assistance having the greatest difficulty accessing it. Parents are therefore forced to negotiate new roles in their child's life as the custodial aspect of school is typically taken from them before they can access all the governmental services and funding that they need and are entitled to.

Services and supports for adults with intellectual disabilities are expensive. Parents balance this cost by applying for funding that is available through the government. Maggie compares access to government subsidies to "individual life support" and simply states that "most families cannot afford to pay, so they need to get the support dollars." In order to access the services and supports that the government provides to adults with intellectual disabilities, their parents must navigate complicated and complex bureaucratic systems, fill out applications and provide supporting documentation. McColl et al. (2017) contend that Canadian disability policy is comprised of various legislation, regulations, programs, and providers which makes it difficult to understand and navigate. The parents in this study provide concrete evidence of the validity of this assertion. They articulate that they face a heavy work load managing services for their intellectually disabled adult children and find this to be a time consuming and labour intensive process. Numerous national and international studies have found that the families of children with intellectual disabilities report significantly higher levels of stress and shoulder a larger economic burden than the parents of typically developing children (Cadman et al., 2012; Ganz, 2015; Van Tangerloo et all., 2015; Vogan, 2014; Zaidman-Zait et al, 2014; Zaidman-Zait et al, 2016). Closer to home, Statistics Canada data indicates that Canadians who care for their intellectually disabled children report high levels of psychological and financial difficulties resulting from their responsibilities (Turcotte, 2013).

Many adults with intellectual disabilities remain reliant on their families for support well into adulthood (Cadman et al., 2012; Robinson et al. 2016; Van Tangerloo et al., 2014; Vogan et al., 2014). This dependency results in significant levels of caregiver burden for the families who continue to provide this needed support. Researching the Quebec based transition experience, Gauthier-Boudreault et al. (2017) found that the families of adult children with disabilities were lacking material, informational, cognitive and emotional support at the time that their child transitioned from school. This finding mirrors the sentiments of the Ontario parents who took part in this research. After their child aged out of high school, parent participants reported relying heavily on other parents for support. Brenda explained that parents of children with intellectual disabilities rely on other parents to pass down their experiences. Parent based support networks were particularly important to participants, as they unanimously faced significant misinformation, complicated processes, and general ineffectiveness when they attempted to access governmental supports for their children after they aged out of high school.

As discussed in the literature review, social supports, such as the parent support networks, have been correlated with lower level of stress (Dyson 1997; Feldman et al. 2002; Robinson, 2016; Smith et al. 2001), distress (Gallagher et al. 2008; Robinson, 2016) and marital problems (Dunn et al. 2001). All the participants who took part in this study spoke favorably about the formal and/or informal parent support networks that they participated in. In addition, they all articulated that they used social networks partly as information vehicles to assist with, and improve, their ability to access government services. The sentiments of the parents who participated in this research are echoed by the support network literature. Law et al. (2002) found that support networks for parents of children with disabilities provided parents with increased skills and an increased sense of power and belonging. They note that, "with the experiences of more than one family behind them, [parents] felt that they had more power in standing up for what they believed in and trying to make change" (Law et al. 2002, p. 43). Similarly, Mandell and Salzer (2007) conclude that support groups are advantagous over one-to-one supports in that participants are afforded an opportunity to give and receive support, the chance to interact with others who share similar experiences, and participate in a pool of knowledge. Likewise, Jackson et al. (2018) studied the perceived value of support groups for parents of children with severe or profound intellectual and developmental disabilities and concluded that parents value the ability of support groups to provide a place where the feel understood and can share and gather information.

In their qualitative study of the transition from youth to adulthood as faced by youth with disabilities, Steward et al. (2013) concluded that there is a dynamic and interdependent relationship between persons and their environment and that there is a ‘good fit’ when there are societal supports in place to facilitate this relationship and a ‘bad fit’ when there are barriers hindering the relationship. As such, the positive, ‘good fit’ benefits of parent support groups must be weighed against the ‘bad fit’ barriers, and resulting burden, that parents come up against when they attempt to access governmental supports for their adult children with intellectual disabilities.

Strategies: Apathy and Advocacy

When it comes to their children’s post high school needs, the participants who took part in this study conclude from their experiences that, when it comes to post high school social services, the government is largely apathetic, ineffective, and just doesn’t care about the needs of their adult children. Senator Munson echoed these sentiments when he asserted that “it's very disturbing, and it's shocking that we're not building that bridge to a better place as opposed to a bridge to nowhere.” Munson expressed grave concerns about the loss of services faced by individuals with intellectual disabilities when they reach adulthood. He is regretful that the government believes that there is a price tag on supporting individuals with intellectual disabilities and asserts that we need to increase taxes to provide people with the supports that they should be entitled to. Similarly, Marge McCabe, of the Families Matter Cooperative, believes adamantly that true progress cannot be realized without legislative change as our current funding model is not based on need but on “what politician is in power and what they want to give.”

To overcome this real or perceived governmental apathy, the parents who participated in this research appear to have developed strong advocacy skills. They play on their individual strengths, they band together in an effort to make their voices louder, and they take on active and vocal roles during times of political change. They faced significant stress, anxiety and uncertainty when their children aged out of eligibility for school-based programs. This was a dark and frustrating time for parents as they sought to navigate barriers and obstacles in their efforts to replace lost services. To overcome these feelings, they asserted control over their situation by coming together, forming support networks and advocating for their children's needs. While the immediacy of their children's transition to post-school life is behind the families that participated in this research, the requirement for them to continue to advocate for their children's needs continues.

Researching parental perceptions of post-school years for young adults with developmental disabilities, Bianco et al (2009) found that parents struggled to find balance between advocating for the needs of their adult children and fostering their independence. Their findings parallel this study as the parents they interviewed sought to advocate for their adult children to receive employment, more and/or different services, and to fight when their children were not given access to what they perceived to be essential supports. Likewise, Nachshen (1999) conducted a study to better understand the relationship between advocacy and stress for families of children with developmental disabilities. As was the case with this study, she concluded that "in order to face the challenges involved in raising a child with a developmental disability, parents must empower themselves by developing the skills to act effectively as advocates" (p. ii).

As discussed in detail in Chapter Four, provincial governments bear most of the burden for the provision of disability supports. Unfortunately, none of Canada's provinces are adequately meeting the needs for these supports. Canadian literature calls for federal disability legislation that is stronger, more cohesive across the country, and more effective than the existing Canadian Human Rights Act and Canadian Charter of Rights (Burns & Gordon, 2010). Further, Canadian researchers point to a need for new and robust legislation to ensure that all provinces have appropriate services and programs available to protect and support individuals with disabilities (Burns and Gordon, 2010). Hamdani (2016) contends that Canadian disability policy is based largely on normative assumptions about adulthood that problematize rather than support the lived realities of individuals with disabilities. She charges policy makers with the task of reshaping disability policy in a way that mitigates unintended harmful consequences and improves the health and daily lives of young adults with developmental disabilities and their family members. Given this, it appears that the opinions of the parents who contributed to this research are in alignment with the views of Senator Munson, the Families Matter Cooperative and that of the larger academic community.

Connection to the Research Questions

The primary research endeavor of this study is to identify how the families of adult children with intellectual disabilities understand and experience the transition that takes place when their children age out of high school. This study builds the understanding of the transition phenomenon on three secondary questions. As such, I will begin by connecting my findings to these secondary questions as I believe they are integral to answering my primary research question. I will then use these connections to fully answer my primary research question.

Secondary question one.

How do the families of adult children with intellectual disabilities understand and experience the school based IEP transition process?

Under Ontario’s Education Act, the Ministry of Education is responsible for ensuring that all exceptional children have access to appropriate special education programs and services without the payment of fees (Education Act, 1990). In Ontario, special education services are available to "students who have behavioural, communicational, intellectual, physical, or multiple exceptionalities [that] require special education programs and/or services to benefit fully from their school experience" (Ontario Ministry of Education, 2018b, para 1). The parents who took part in this study relied on these special education programs, and the teachers who implemented them, to care for, nurture, and educate their children.

Regardless of completion, Ontario's Education Act (1990) terminates high school services the year that a student turns 21. To prepare for this, Ontario has adopted strong transition planning policies and requires that all Individual Education Plans include a transition plan for students age 14 and over (Education Act, 1990). The Ontario Ministry of Education (2002) contends that these policies are intended to help exceptional students make a successful transition from school to work, further education, or community living. Built on what Klein, Tye and Goodlad (1975) call the ideal curriculum, these policies are ratified as formal documents by the Ontario Ministry of Education. Much of the transition planning literature focusses on the act of planning. In this regard, issues such as individual agency and the involvement of key stakeholders during the planning process take centre stage in many empirical studies of transition (Croke & Thompson, 2001; Hanger et al., 2014; Griffen et al., 2014; Jackett, 2010). The parents who took part in this research all supported and participated, to varying degrees, in Ontario's mandated IEP transition planning process for their children. Hoping to foster independence, they all asked that their children learn applicable life and job skills as part of this transition plan. Given that these parents felt included in the creation of their child's transition plan, it can be asserted that their children's schools were employing best practice transition planning practices. Further, it can be concluded that their children's schools were fulfilling their obligations at the perceived and operational levels (Klein, Tye & Goodlad, 1975). However, as only parents were interviewed in this research, it is impossible to comment on the experiential curriculum experienced by the students themselves. Despite seeming adherence to best practice policies, Wehman (2014) notes that the long term measured impact of person centered transition practices have been postulated rather than systematically reviewed. As such, current best practice policies, such as those used by the Ontario Ministry of Education, are built on assumptions rather than on successful transition outcomes.

Parent participants spoke highly of their children's former teachers and believe that these teachers had good intentions when they drafted IEP transition plans for their children. Nonetheless, they have been left to conclude that these plans were destined for failure. They attribute this failure not to the inadequacies of the process, but to that of the larger system. Post high school, these parents have found an undersupply of essential services for their children amidst an expanding demand. Marge McCabe asserts that this finding is not limited to my research sample as she has observed countless families struggle to access planned-for services in her work at the Families Matter Cooperative. This assertion finds further evidence in my news media analysis as nearly two thirds of the articles that the *Toronto Star* and *CBC* published about the adult lives of individuals with intellectual disabilities concerned the wait that they endure to access housing, day services and provincial funding. Researchers have postulated that an inability to guarantee the availability of planned-for services is a limitation of person centered planning (Clases et al., 2010; Dowling, Mansell & Beadle-Brown 2004; Manthorpe, & Cowley 2007; Kaenne & Beyer, 2014). The findings of my research provide evidence for the validity of this hypothesis.

I conclude that the parents who participated in this research view the school based IEP transition process as an exercise in futility. Ontario's transition planning policies are sound and parents are confident that strong transition plans are created in Ontario schools. It would appear, however, that the realities of our social system may not be considered during the drafting of these plans. Given the disconnect between what is planned and what is actually possible, families struggle to realize the planned transition and are ultimately let down by Ontario's school based IEP transition process when their adult children age out of high school services.

Secondary question two.

How do the transition variables outlined in Schlossberg's 4 Ss model (situation, self, support, and strategies) affect the way families experience the transition that takes place when their intellectually disabled adult children age out of high school?

This study indicates that the parents of children with intellectual disabilities work to prepare for the ***situation*** that they know they will face when their children turn 21 and age out of provincial school eligibility in Ontario. The act of planning for this transition can be seen to alleviate some of the load carried by parental caregivers as it facilitates the provision of informational supports. The literature surrounding caregiver burden correlates informational support with lower levels of reported burden (Dyson 1997; Feldman et al. 2002; Robinson, 2016; Smith et al. 2001). Leading up to this event, IEP transition planning may, therefore, be a useful tool to reduce the real or perceived burden among the parents of children with intellectual disabilities. However, despite this knowledge and preparation, this research finds that when parents try to access the services their adult children should be entitled to post-school, they face long wait lists, bureaucracy and a system that is difficult to navigate. As such, this research indicates that the benefits of transition planning are not enduring.

As their children aged out of school, the parents who participated in this study experienced stress and significant financial burdens. After losing access to high school services, they sought to provide their children with the best supports and services available despite their relative socioeconomic positions. Services and supports for individuals with intellectual disabilities are expensive. The parents who took part in this study could only rely on their ***self*** to balance this cost - and thereby reduce their objective burden - by applying for funding and services available through the government. Bond and McColl (2007) note that service recipients perceive Canadian disability policy as complex and difficult to navigate. This assertion is supported by the findings of various other academics who have probed Canadian disability policy (Boyce et al., 2001; Cameron & Valentine; 2001; McColl et al., 2007; Prince, 2004) and is clearly articulated by the parents who participated in this study. As such, this research suggests that those who are better at navigating governmental bureaucracy may hold an unfair advantage in their efforts to secure services for their adult children.

To help themselves cope with bureaucratic challenges and service inaccessibility the parents who participated in this research turned to ***support*** networks. There is a significant body of research that indicates that membership in formal and informal social support networks has a positive impact on the subjective burden of families who provide informal care to children with intellectual disabilities (Dyson 1997; Feldman et al. 2002; Greenlee et al. 2006; Robinson, 2016; Smith et al. 2001). All the participants who took part in this study spoke favorably about the formal and/or informal parent support networks that they participated in. In addition, they all articulated that they used social networks partly as information vehicles to assist with, and improve, their ability to access government services. In their related research, Steward et al. (2013) contend that a dynamic and interdependent relationship exists between persons and their environment and that there is a 'good fit' when there are societal supports in place to facilitate this relationship and a 'bad fit' when there are barriers hindering this relationship. Building on these findings, my research indicates that the positive, 'good fit' benefits that parents glean from their involvement in support networks are offset by the 'bad fit' barriers, and resulting burden, that parents experience when they endeavor to access governmental supports for their adult children with intellectual disabilities. Accordingly, I postulate that there is a cyclical relationship between the burden alleviated through parental supports and the burden produced through parental dealings with Ontario's services and programs for individuals with disabilities.

Barriers to service ultimately led the parents who participated in this research to conclude that they have unmet needs and rights that should be rectified through legislation. They assert that, when it comes to the social services that their children need, the government is apathetic, ineffective, and just doesn't care about the needs of their family. To manage this reality, parent participants relied heavily on their own advocacy as a ***strategy*** to overcome these barriers. In his research on Canadian disability policy, Prince (2004) notes that Canadians with disabilities voice divergent views and goals relative to those held by the government. Various policy analysts agree with this assertion and contend that Canadian disability policies continue to be built on a medical model of disability as they are framed around the recipients' basic personal and financial needs rather than the recipients' abilities, aspirations and/or potential (Degener, 2016; Prince, 2014; Jongbloed 2003; Pooran & Wilkie, 2005). Conversely, the perspectives of individuals touched by disability are more typically rooted in the social and human rights models of disability which espouse anti-discrimination and individual civil, political, economic, social and cultural rights (Degener, 2016; Haegele & Hodge, 2016; Maholtra, 2012; Oliver 1999; Pooran & Wilkie, 2005). Given this discrepancy, my research indicates that parents strive to bridge this ideological gap by lobbying the government to enact new legislation that clearly aligns with their needs and expectations.

Secondary question three.

How do families experience disability legislation and policy in Canada and Ontario as their adult children with intellectual disabilities age out of high school?

In 1977, Brown set out to identify the state of Canadian services and programs for individuals with disabilities. She identified numerous shortcomings in Canada's delivery of services for individuals with disabilities including service gaps, delayed referrals, inadequate follow-up programs and a lack of linkages between the various social programs. In 2004, Prince undertook a similar review of Canadian services and programs and concluded that little had been done to rectify the shortcomings that Brown had identified a quarter century earlier. Almost a decade and a half later, in 2019, I contend that Brown's 1977 review remains a realistic description of Canada's current state of disability policy. I base this conclusion on three main factors; (1) Canada has yet to develop a normative foundation, philosophy or model of disability. Without this foundation, Canadian has struggled to create, harmonize, and evaluate its own disability policy (Jongbloed, 2003; Prince 2004); (2) Although many have called for its creation, Canada lacks of a national strategy to unify the differing practices that exist in the various provinces and territories across Canada (Burns and Gordon, 2010; Scott, 2016). Without a national strategy, differences and inequities are inevitable in the various disability services and supports offered across Canada (Jongbloed, 2003; Prince 2004); and (3) Canada's federal and provincial governments have struggled to develop a funding mechanism for disability services and supports that ensures the provision of fair and equitable services and incorporates fiscal restraint and debt reduction policies.

Models of disability and Canadian disability policy have changed and evolved over time. This ongoing discourse and subsequent reframing of disability has inhibited the development of a normative foundation, framework or lens upon which Canadian disability policy can be designed and evaluated. Jongbloed (2003) notes that Canadian disability policies developed under these various models have layered upon, rather than replaced one another. Subsequently, many historical policies fail to align with current Canadian societal expectations. As a result of this layering, McColl (2017) contends that Canadian disability policies have become a "patchwork of legislation, regulations, programs, providers and entitlements" (p. 7). Accordingly, many policy analysts conclude that Canadian disability policies have become extremely complex and difficulty to navigate (Bond & McColl, 2013; Cameron & Valentine, 2001; Prince 2004). The parents who participated in this research affirm this finding and note that they have faced and continue to face significant barriers and challenges navigating governmental programs and services for their adult children. They articulate worry for parents who may be less adept, or have less time to allocate to this task, and they rely heavily on social networks in their endeavors to navigate and access these services.

Canada's federal government offers a small number of programs that provide financial assistance and subsidies to individuals with disabilities. The bulk of the actual provision of disability services falls mainly to the individual provinces and territories. Consequently, many policy theorists assert that provincial responsibility for disability services, supports and policy has created differences and inequities across the various regions of Canada (Burns & Gordon, 2010; Bond & McColl, 2013; McColl et al, 2017). Since the early 1980s, there has been governmental recognition of the need for a national strategy to address and unify the differing practices and services offered to the disabled across Canada's various provinces and territories

(Burns & Gordon, 2009; Disability and Information Research Alliance, 2006). Numerous reports by federal, provincial, and territorial Ministers responsible for social services have called for the integration of services across Canada (Burns & Gordon, 2009). Despite this, Canada's current Liberal government has chosen to direct focus on accessibility rather than a national strategy. Organizations and individuals that advocate for and support people with disabilities, however, continue to lobby for a national strategy. Although he was speaking specifically about autism services, Senator Munson spoke fervently of the need for a national strategy to unify services for individuals with disabilities. The families who participated in this research echoed Munson's assertion in their proclamations that legislation is desperately needed to ensure that their adult children are granted access to the services and supports that they need to live quality lives. Left with little choice, these parents feel compelled to stand up and lobby the government to enact new policies that better meet the needs of their families.

Facing an increased focus on deficit reduction, the Canada Assistance Plan (CAP) was replaced with the Canada Health and Social Transfer Program in 1996 under Jean Chretien's federal Liberal government. This change saw transfer payments from the federal government to the providences drop by nearly four billion dollars in the first fiscal year following the funding change (McIntosh, 2004). When CAP was abandoned in 1996, it was called a "recipe for social disaster" (Dodson, 1996) as, along with reducing the amount of funding allocated to the provinces, the federal government also reduced their ability to influence how the provinces would spend the money transferred to them for education, health care and social services. The provincial ability to allocate federal transfer dollars as provinces deem appropriate creates a situation wherein programs and services for individuals with disabilities compete for dollars with all other areas of social services, as well as with the health care and education sectors. All funded public sectors can articulate unmet needs and make sound cases for increased funding. In this regard, the parents who participated in this research are no different and they strongly articulated a clear need and demand for disability services and supports which require funding commitments from both Canada's federal and provincial governments.

Although Canada has demonstrated some commitment to disability policy, my research indicates that Canada has struggled to reach the level of commitment necessary to develop the normative foundation, national strategy and stable funding required to fully meet the needs of Canadians with disabilities. Consequently, the parents who took part in this research have faced significant barriers in their endeavors to access governmental services and supports after their children aged out of high school. All told, their experiences contending with these barriers has led the parent participants of this study to conclude that they have unmet needs and rights that should be rectified through legislation.

Primary research question.

How do the families of adult children with intellectual disabilities understand and experience the transition that takes place when their children age out of high school?

This study indicates that the parents of children with intellectual disabilities work to prepare for the situation that they know they will face when their children turn 21 and age out of provincial school eligibility in Ontario. Ontario's transition planning policies are based in best practice and parent participants did not articulate a desire to change or add anything to this process. Despite this, they have unanimously come to view the IEP transition planning process as an exercise in futility. This is due, in large part, to the fact that they see the realities of our social system as being at odds with their children's IEP transition plans. Despite knowledge and preparation, this research finds that when parents try to access the services their adult children should be entitled to post-school, they face long wait lists, bureaucracy and a system that is difficult to navigate. Consequently, participants have struggled to realize the planned-for transition and ultimately feel let down by Ontario's school based IEP transition process when their adult children age out of high school services.

The parents who participated in this research recognize that their children have unique needs and contend that these needs were largely met when their children were in school. If given the choice, these parents articulate that they would leave their children in the school system indefinitely. Faced with the reality of the loss of these services, however, parent participants found themselves struggling to replace lost custodial care hours without sacrificing the quality of the programming afforded to their children. In this endeavor, they experience stress and significant financial burdens. To help themselves cope with these challenges, they turn to support networks, often as a tool to give voice to their frustrations and as a mechanism to help overcome the barriers they face in their attempts to access needed services. These barriers to services ultimately led parents to conclude that they have unmet needs and rights that should be rectified through legislation. Because the desired legislation is not forthcoming and parent participants continue to have unmet needs, they assert that the government is apathetic, ineffective, and just doesn't care about the needs of their families.

Canada, for many reasons, has been unable to develop the normative foundation, national strategy and stable funding required to fully meet the needs of Canadians with disabilities. The inevitable interrelationship of these three factors in acknowledged. As asserted in the policy chapter, the development of a normative foundation could potentially lead to the development of a national strategy. Should Canada look first to the development of a national strategy, doing so would require the development of some type of framework upon which to base that strategy. A funding mechanism for the outcomes associated with developing either a normative foundation and/or a national strategy would be essential. Essentially, then, tackling any of these three contributing factors could potentially mean exploring solutions to all three of them. If these factors were to be approached collectively, the resolution of all three could potentially provide powerful tools to enable a fair and uniform system of disability support across Canada. It is, however, an overwhelming task that would require unprecedented commitment, collaboration, a strong will to act and a healthy appetite for change. Given this, achieving change on the scale that these parents desire and advocate for is unlikely.

Ultimately, then, it appears that these parents will continue to face challenges that will not be rectified through legislation in the foreseeable future. Nonetheless, these parents persevere. They can’t stop trying, they can’t stop advocating, and they can’t stop hoping for change.

Chapter Ten: Conclusion

Thesis Summary

Transition planning in Ontario schools is intended to help exceptional students make a successful transition from school to work, further education, or community living (Ontario Ministry of Education, 2002). Theoretically, transition planning is meant to address many of the challenges that are currently faced by Ontario families. With this study, I entered into a phenomenological exploration of the lived realities faced by the parents of children with intellectual disabilities as they navigate life after high school. Conducting a phenomenological study allowed me to delve into the perceptions, perspectives, understandings and feelings of parents who have experienced this transition. I accomplished this using in-depth interviews conducted with a small sample of participants. My research focusses on commonalities and provides a composite description of the essence of the experience of the transition to post-school life as faced by the families of individuals with intellectual disabilities.

Throughout my data collection and subsequent analysis, I relied on methods common to interpretative phenomenology to guide my process and ensure its viability. To this end, I have conducted a phenomenological analysis of participant narratives and provided a comprehensive portrayal of how parents experience and understand the transition that takes place when their adult children with intellectual disabilities age out of school. The many elements presented in this thesis illustrate the disparities between Ontario's best practice IEP transition planning practices and the reality of its social services. Despite knowledge and preparation, the Ontario parents who participated in this research faced long wait lists, bureaucracy and a system that is difficult to navigate in their endeavors to access the services their adult children should be entitled to post-school. The following sections will discuss the implications and limitations of this study and make a case for further research.

Limitations, Recommendations and Contributions

This phenomenological study offers a preliminary window into the ways in which parents experience the transition that takes place when their adult children with intellectual disabilities age out of high school services in Ontario. In his writings on phenomenology, Max Van Manen (2016) postulates that those reading interpretive texts “must write what the author forgot, over-looked, could not ‘see’ or ‘hear’ or remember” (p. 8). Expanding on this, he asserts that interpretive texts invite the reader to “deepen them, to enrich them, to personalize them, and to hold them against the brightness of the living daylight.” (p. 8). Thus, Van Manen (2016) cautions readers to be aware that phenomenological studies do not yield absolute truths as “no interpretation is ever complete, no explication of meaning is ever final, no insight is beyond challenge” (p. 7).

Phenomenological inquiry focuses on the essence of the lived experience of a specific group of individuals but does not purport to produce generalizable data. As such, the results of this study are built on the first-hand accounts of a relatively small number of individuals. Many in the research community have divergent ideas about the number of participants that constitute a representative sample in qualitative research (Cresswell, 2017; Guest 2006; Mason, 2010; Morse, 1995). My sample of five parents falls on the low end of these requirements. This is further problematized by the fact that these five individuals comprise a homogeneous group of relatively well off, white participants. Further, the parents who participated in this research had the willingness, ability, and means to provide support and to advocate for their children whenever needed. Many families and adult children with intellectual disabilities are not so fortunate.

While Mason (2010) points out that there is little empirical evidence as to why various sample sizes are deemed appropriate, I believe that more research is needed to verify the commonality of my findings across a wider and more diverse participant profile.

As discussed at the onset of this thesis, this study excludes the voices of individuals with intellectual disabilities. Because of this exclusion, the way that these individuals experienced and perceived their own transition from high school into the adult world is not considered in this research. Within the parameters of this study, I did not believe that I could include the voices of individuals with intellectual disabilities in a meaningful way. Consequently, I purposefully heeded the advice of the emancipatory and participatory paradigm critics and opted to gather the transition stories of individuals with intellectual disabilities through the voices of their closest allies, their parents. I recommend further research that meaningfully captures this experience from the point of view of the young adults themselves.

Phenomenological researchers must be ever vigilant in their efforts to exclude their own beliefs and opinions from their findings. I relied heavily on the strategies to achieve bracketing proposed by Chan et al. (2003) to ensure I remained neutral and impartial in this phenomenological research. Despite this, all phenomenological studies require interpretation and the subjectivity of this process makes it difficult to establish firm reliability and validity. I believe that I fully committed to the bracketing procedure thereby minimizing my influence on the results of this research. Additional research into this transition experience, however, is required to build upon the findings presented here.

Although Ontario has strong written transition planning policies, there is very little research regarding the effectiveness and outcomes of these policies for exceptional students and their families. A thorough review of the literature shows that there is little to no significant research into the long term effectiveness of transition planning on a national or international level and, therefore, this study may provide a starting point for new national and international research. On paper, Ontario's transition planning regulations appear to foster a person centered approach, but the degree to which individuals, their families, and community members are actually involved in the process remains unclear. Consequently, I believe that outcomes-based research that follows young adults well into their post-school lives is required in order to assess the success of Ontario's transition planning model.

My research identified a significant disconnect between the services and supports that the transition planning process identifies as required when school-based supports end, and the actual availability and/or accessibility of these identified services post-school. Given this, research into strategies that resolve the knowledge gap at the school transition planning stage would be helpful.

My research reinforced the findings of numerous other researchers that Canada's disability policies and services are woefully inadequate, underfunded and difficult to navigate. As detailed in the chapter on policy and legislation, there are no readily apparent or easily implemented solutions to this situation. That said, I would still recommend further research into potential strategies that expand the availability of services to individuals with developmental disabilities, as well as potential strategies that would simplify the access to these services.

Final Words

Building an understanding of the transition that takes place when young adults with intellectual disabilities age out of Ontario's publicly funded school system is a multifaceted undertaking. The foundations of this understanding are presented in the foregoing chapters. In these chapters, I have strived to embed this study within the framework of the existing literature and policy pertaining to this transition. I have enhanced this research with an original content analysis of news articles pertaining to the post-school lives of adults with intellectual disabilities. I also undertook interviews with community and government representatives. Finally, I have conducted a phenomenological analysis of participant narratives and provided a comprehensive portrayal of how parents experience and understand the transition that takes place when their adult children with intellectual disabilities age out of school. When taken together, these elements illustrate how difficult it is for the parents of young adults with intellectual disabilities to replace the services and supports that they lose when their adult children age out of high school in Ontario. Based on the personal stories presented in this research, I contend that, despite best practice transition planning policies in Ontario schools, the difficulties families face post transition lead them to conclude that their adult children with intellectual disabilities experience significant unmet needs and rights after aging out of the school system and that this untenable situation should be rectified through legislation. Consequently, many have come to view the time and effort that goes into planning for unattainable services as akin to the building of a bridge to nowhere.

As a special education teacher, this research leads me to believe that more must be done to ensure that the transition plans that we work so hard to create are viable and attainable by the young adults they are created for. I am hopeful that the newly amalgamated Ontario Ministry of Children, Community and Social Services is able to help bridge the decline and gaps in services that the families who took part in this research report experiencing. On a personal level, I agree with the consensus found in this research that legislation is the only way to achieve the lasting change that ultimately mandates the provision of supports and services for adults with intellectual disabilities once they transition out of high school. From an academic perspective, however, I must acknowledge that legislative change of the scope required will be extremely difficult. As detailed in the chapter on policy and legislation, Canada’s disability policy has been deemed ‘hit or miss’ since the 1970s. The reasons for this are varied and many. The biggest by far, however, is the question of where funding will come from. This funding question is further complicated by both the federal and provincial governments’ need to find a balance between providing the social benefits required to fully support and enable its disabled population while, at the same time, maintaining policies of fiscal restraint and debt reduction. Additionally, funding for the disabled population competes with funding for numerous other government accountabilities including health care and education. So, while not impossible, the type of legislative change that the participants in this study advocate for would require governmental prioritization that elevates disability policy above numerous other competing demands.

While this research concludes with a somewhat negative outlook on the possibility of significant legislative change, that negativity is somewhat offset by the strength and endurance shown by the participants in this study. These parents fight tirelessly for their adult children. They advocate for change and they unite their voices into strong community groups. This leaves me with one last recommendation for potential future research into the advocacy techniques and strategies that may ultimately help these many voices lobby successfully for the legislative changes they so deeply desire.

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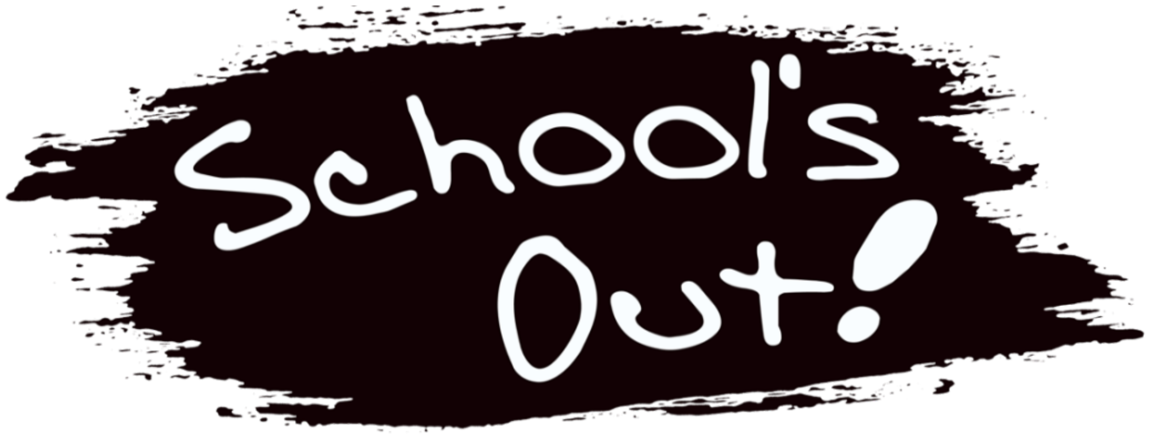
Appendix A: Recruitment Poster



Are you a young adult, or the parent of a young adult, with an exceptionality or disability? Did You or Your Child Recently Finish High School?

We are looking for volunteers to take part in a study of the experiences of transition planning in Ontario high schools

Your participation would involve taking part in an interview session that will take approximately one hour to complete and will be scheduled at a time and place that best suits you.

For more information about this study, or to volunteer for this study, please contact:
Katrina Isacsson, Faculty of Education, University of Ottawa

This study has been reviewed by, and received ethics clearance by the University of Ottawa Research Ethics Board.

Appendix B: Information Letter

Title of the Study: Experiences of Transition Planning in Ontario High Schools.

Dear Sir or Madam:

My name is Katrina Isacsson and I am a PhD candidate at the University of Ottawa. I am also a special education teacher for the Ottawa Carleton District School Board.

I am looking for people to participate in a study that I am conducting. This study is about the way students and their families experience transition Planning in Ontario High Schools.

If you choose to participate in my study, your participation will involve taking part in an interview session that will take around one hour to complete and will be scheduled at a time and place of your choice.

Your participation in this study will allow me to collect information that will be used to better understand how young adults and their families experience the transition from high school to adult life.

Any information that you share will remain private and will be used only for this research project.

It is your choice to participate in this study. If you choose to participate, you may stop at any time. If you decide that you do not want to participate any more, any information you have provided will be deleted. You can choose to only answer some questions or to answer all of them.

If you have any ethical concerns about your participation in this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, 550 Cumberland Street, Room 159, Ottawa, Ontario K1N 6N5, (613) 562-5841, ethics@uottawa.ca.

If you have any questions about the study, you may contact the researcher, or the researcher's supervisor.

Researcher: Katrina Isacsson, Faculty of Education, University of Ottawa

Supervisor: Prof. Lorna McLean, PhD, Faculty of Education, University of Ottawa

You may keep a copy of this letter.

Appendix C: Consent Form (Parent or Guardian)

Title of the Study:	Experiences of Transition Planning in Ontario High Schools.
Researcher:	Katrina Isacsson, Faculty of Education, University of Ottawa
Supervisor:	Prof. Lorna McLean, PhD, Faculty of Education, University of Ottawa
Invitation to Participate:	You are invited to participate in the above mentioned research study conducted by Katrina Isacsson and supervised by Professor Lorna McLean.
Purpose of the Study:	The purpose of the study is to develop an understanding of how exceptional young adults and their parents or guardians experience their transition out of high school and into adult life.
Participation:	Your participation will involve taking part in an interview session that will take approximately one hour to complete and will be scheduled at a time and place that best suits you.
Benefits and Risks:	Your participation in this study will allow the researcher to collect data that will be used to better understand how exceptional young adults and their families experience the transition from high school to adult life. All interactions, including participation in this research, have the potential to be emotionally or psychologically taxing. To counter this potential, all research participants will be carefully monitored for signs of distress, disinterest or unwillingness to cooperate. If an individual appears to display any of these signs, I will ensure that he/she has the power to withdraw the consent given either by themselves, or on their behalf, and be removed from the study.
Confidentiality and Anonymity:	The information you share will remain strictly confidential. The contents of the interview session will be used only for the purposes explained above. Your confidentiality will be protected and interviewees will not be identified.
Conservation of data:	Interviews will be digitally recorded and transcribed into text documents. At your request, a password protected copy of your transcribed interview will be sent to you for review. Digital recordings and transcriptions will be kept on the researcher's computer in a password-protected file. All data will be securely destroyed five years after the completion of this project.
Compensation:	There is no compensation for participating in this study.
Voluntary Participation:	You are under no obligation to participate in this study. If you choose to participate, you may withdraw from the study at any time. Should you choose to withdraw, any data you have provided will be deleted. You may refuse to answer any questions, without suffering any negative consequences.

If you have any questions about the study, you may contact the researcher, or the researcher's supervisor, at the coordinates listed above.

If you have any ethical concerns regarding your participation in this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, (613) 562-5387, ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

Accept: I, ______________________________, **agree to participate** in the above research study conducted by Katrina Isacsson of the Faculty of Education. This research is under the supervision of Professor Lorna McLean.

Accept: I, ______________________________, **consent to the digital recording** of the interview session I participate in.

Decline: I, ______________________________, **do not wish to participate** in the above research study conducted by Katrina Isacsson of the Faculty of Education. This research is under the supervision of Professor Lorna McLean.

.

Participant's signature: __________________________ Date: __________________________

Researcher's signature: __________________________ Date: __________________________

Appendix D: Consent Form (Government or Advocacy Organization)

Title of the Study:	Experiences of Transition Planning in Ontario High Schools.
Researcher:	Katrina Isacsson, Faculty of Education, University of Ottawa
Supervisor:	Prof. Lorna McLean, PhD, Faculty of Education, University of Ottawa
Invitation to Participate:	You are invited to participate in the above mentioned research study conducted by Katrina Isacsson and supervised by Professor Lorna McLean.
Purpose of the Study:	The purpose of the study is to develop an understanding of how exceptional young adults and their parents or guardians experience their transition out of high school and into adult life.
Participation:	Your participation will involve taking part in an interview session that will take approximately twenty minutes to complete and will be scheduled at a time and place that best suits you.
Benefits and Risks:	Your participation in this study will allow the researcher to collect data that will be used to better understand how exceptional young adults and their families experience the transition from high school to adult life. All interactions, including participation in this research, have the potential to be emotionally or psychologically taxing. To counter this potential, all research participants will be carefully monitored for signs of distress, disinterest or unwillingness to cooperate. If an individual appears to display any of these signs, I will ensure that he/she has the power to withdraw the consent given either by themselves, or on their behalf, and be removed from the study.
Confidentiality and Anonymity:	The contents of the interview session will be used only for the purposes explained above. The information you provide will not remain confidential and your anonymity will not be protected.
Conservation of data:	Interviews will be digitally recorded and transcribed into text documents. At your request, a password protected copy of your transcribed interview will be sent to you for review. Digital recordings and transcriptions will be kept on the researcher's computer in a password-protected file. All data will be securely destroyed five years after the completion of this project.
Compensation:	There is no compensation for participating in this study.
Voluntary Participation:	You are under no obligation to participate in this study. If you choose to participate, you may withdraw from the study at any time. Should you choose to withdraw, any data you have provided will be deleted. You may refuse to answer any questions, without suffering any negative consequences.

If you have any questions about the study, you may contact the researcher, or the researcher's supervisor, at the coordinates listed above.

If you have any ethical concerns regarding your participation in this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, (613) 562-5387, ethics@uottawa.ca

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Decline: I, _____________________________, **do not wish to participate** in the above research study conducted by Katrina Isacsson of the Faculty of Education. This research is under the supervision of Professor Lorna McLean.

.

Participant's signature: _________________________ Date: _________________________

Researcher's signature: _________________________ Date: _________________________

Appendix E: Parent Interview Guide

Please tell me about:

1. The transition planning that occurred before your child finished school.
2. The process and experiences of your child finishing school and moving on.
3. The services and supports that you receive from the government.
    a. Could the government could do anything to better address your child’s needs?
4. Your experiences with your child post-graduation.
    a. Do you have any advice to offer a similar family with a child who is on the cusp of aging out of the school system?

Appendix F: Advocacy Organization and Government Representative Interview Guide

1. How does the transition planning that occurs in Ontario schools prepare young adults and their families for the transition from school to post school life?

2. What is the biggest challenge that exceptional young adults and their families face once they graduate or age out of the Ontario school system?

3. Theoretically, there are a number of services and supports available to young adults once they graduate but, in reality, the services are difficult to access because of waiting lists, selection and entry criteria, etc. Given this, what could potentially be done to make access to these services easier?

4. How could/should the Ontario government support these young adults and their families?

5. Do you have suggestions for how the transition from school to post school life could be improved - things the school boards, ministries, families and or students themselves could do to make this transition better?

Appendix G: CBC News Articles Analyzed in Content Analysis Chapter

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Aging parents look to provide for disabled children (2013, Dec 12) *CBC News*. Retrieved from http://www.cbc.ca/news/canada/toronto/aging-parents-look-to-provide-for-disabled-children-1.2462013

Albertans worry about care gap for young adults with special needs (2012, Dec 11). *CBC News*. Retrieved from http://www.cbc.ca/news/canada/calgary/albertans-worry-about-care-gap-for-young-adults-with-special-needs-1.1154859

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Drews, K. (2015, Nov 8). Parents struggle to find homes for teens growing up with autism. *CBC News*. Retrieved from http://www.cbc.ca/news/canada/british-columbia/autism-teens-residence-tsunami-care-lack-of-1.3309653

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I am his only friend. What will happen to my son? (2018, May 27). *CBC News*. Retrieved from http://www.cbc.ca/news/canada/newfoundland-labrador/adult-with-autism-falling-through-cracks-1.4668725

'I'm scared to death,' says mother whose autistic son will lose government funding in two years (2017, Feb 10). CBC News. Retrieved from http://www.cbc.ca/news/canada/windsor/windsor-lisa-gretzky-disabled-funding-1.3975623

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Disabilities report a welcome step. (2016, Sep 04). Toronto Star. Retrieved from https://search.proquest.com/docview/1816412566?accountid=14701

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Goffin, P. (2017, Jul 09). Deborah cross was just 56 years old when she left.... Toronto Star Retrieved from https://search.proquest.com/docview/1917174862?accountid=14701

Gordon, A., & Monsebraaten, L. (2013, Feb 09). Auditor targets autism services.Toronto Star. Retrieved from https://search.proquest.com/docview/1285269413?accountid=14701

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