Evaluation of a Knowledge Translation Process in a Community Service Agency:

Supporting the Sexuality of Adults with Intellectual Disabilities

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Abstract

The objective of this dissertation was to evaluate an integrated knowledge translation intervention in a community-based service agency providing services to adults with intellectual disabilities. The dissertation had two objectives: 1) to understand how stakeholders create knowledge, collaborate, and make decisions to implement knowledge on supporting sexuality, and 2) to examine the underlying processes of integrated knowledge translation and how these interplay in the context of community and intellectual disability research. First, we conducted a scoping review to identify strategies to support the sexuality of persons with intellectual disabilities. This knowledge was made available and discussed with stakeholders of the participating agency (i.e., persons with intellectual disabilities, front-line staff, caregivers, supervisors, and senior management) using various methods such as focus groups, an evidence brief and a stakeholder dialogue. Data collection included transcripts of discussions with stakeholders, facilitator notes, notes from the primary researcher, and two self-report questionnaires. The intervention resulted in two in-person workshops and an online program on sexual health for persons with intellectual disabilities and front-line staff. Second, we identified barriers and facilitators to conducting an integrated knowledge translation intervention in a community and disability setting. These included power dynamics and the accessibility of the integrated knowledge translation intervention to knowledge users. The findings from these two aims presented in this dissertation inform changes that may further increase the relevance and applicability of knowledge translation interventions in the community and disability setting.

Chapter 1 – General Introduction

Overview

Research evidence and knowledge should be made available to those who will make use of them. However, the process of moving research evidence into practice is slow. Furthermore, creating knowledge through primary research, synthesizing knowledge using reviews, and disseminating knowledge through journal publications and presentations is insufficient to bridge the gap between evidence and practice (Straus et al., 2010). This highlights the importance of facilitating the translation of knowledge. Generated knowledge use is increased using knowledge translation (Grunfeld et al., 2004). More specifically, researchers recognize the importance of collaboration with knowledge users throughout the research process (Graham et al., 2018). This method, known as integrated knowledge translation, balances the researcher's and knowledge users' expertise (Davies et al., 2008). It engages knowledge users early into the research process, increasing the relevance, applicability, and impact of implemented practices (Gagliardi et al., 2016; Jull et al., 2017).

Integrated knowledge translation is critical in intellectual disability research. Persons with intellectual disabilities have historically been excluded from research. Through integrated knowledge translation, they may actively participate in the creation and implementation of knowledge that impacts their lives. Knowledge translation in intellectual disability research is facilitated through increased exchanges with stakeholders, working with community organizations, and having more accessible research (Shooshtari et al., 2014). Additionally, this increased collaboration with relevant stakeholders (i.e., decision-makers, researchers, and service providers) may inform the implementation of knowledge that increases the quality of life of people with intellectual disabilities (Shooshtari et al., 2014; Spassiani et al., 2016). Although this

is an interesting approach, researchers know little about the underlying processes of knowledge translation (Kothari & Wathen, 2012; Lillehagen et al., 2016).

Limited studies have explored how to conduct knowledge translation with persons with intellectual disabilities (Martin et al., 2010; Shooshtari et al., 2014). Most studies have focused on knowledge translation in the healthcare sector (Goldner et al., 2011). Knowledge translation processes may differ in community-based settings (Contandriopoulos et al., 2010; Kothari & Armstrong, 2011) due to the increased importance of stakeholders' collaboration for decision-making compared to healthcare settings (Kothari & Armstrong, 2011). It is thus essential to evaluate the underlying processes of integrated knowledge translation to identify barriers and facilitators specific to intellectual disability and community research. This may, in turn, lead to changes in policies and practices to better support persons with intellectual disabilities (Martin et al., 2010).

This thesis aimed to translate knowledge and implement change in practices that support the sexuality of adults with intellectual disabilities. Grol & Wensing's Implementation of Change Model guided the knowledge translation intervention methods (Grol, Wensing, et al., 2013). The evaluation of the intervention is a critical component of effective implementation of change (Grol & Wensing, 2013). More specifically, the primary researcher[1] evaluated the application of Grol and Wensing's Implementation of Change model (2013) in a not-for-profit, community-based organization in Ontario, Canada, providing support to adults with intellectual disabilities. The knowledge translation process focused on supporting the sexuality of adults with intellectual disabilities. The project had two main components: 1) an integrated knowledge translation

[1] Primary researcher refers to the author of this dissertation, Natasha Plourde (NP).

intervention aimed at translating knowledge into practice, and 2) an evaluation of the process of conducting this knowledge translation intervention.

Using knowledge translation to implement change and evaluating this process may provide information on interventions to fill the gap between scientific evidence and current practice. Furthermore, the need for strategies, policies, or tools for service providers to better provide social skills training, promote sexual autonomy, and support the sexuality of adults with intellectual disabilities is indisputable (Evans et al., 2009; Swango-Wilson, 2008; Wilkinson et al., 2015). This is particularly important in the context of a community-living approach where service providers' role is to nurture the person's relationships with community members.

We present this dissertation as a traditional monograph with five subsequent chapters. The first chapter presents the background literature on knowledge translation and implementation science and their application in community settings. Furthermore, we describe the target population and barriers to supporting the sexuality of persons with intellectual disabilities. Chapter 2 details the methods used for both the intervention to translate knowledge into practice and the process evaluation of this intervention. In Chapter 3, we present details on the knowledge identified through a scoping review on strategies to support the sexuality of adults with intellectual disabilities. This was the foundation of all the remaining study activities as it was this knowledge that the primary researcher translated within the participating community-based service agency. Chapter 3 explores how knowledge was contextualized and applied to the participating agency, disseminated to relevant stakeholders, and transformed to implement a strategy that addresses the needs of the target community-based agency. The implemented strategy was a sexual education program for adults with intellectual disabilities and their support staff. Chapter 4 presents the process evaluation findings of an integrated knowledge translation

intervention. It contains a description of all project activities, an integration of findings, and the evaluation of the entire process. In Chapter 5, we discuss the main findings and the contribution to research and practice to support the inclusion of persons with intellectual disabilities in knowledge translation research.

Background Literature

Integrating research evidence into practice and policy is a major challenge for researchers. The process of moving research evidence to those who will use and benefit from this knowledge is slow (Dew & Boydell, 2017). It takes approximately 17 years for healthcare evidence to reach practice (Morris et al., 2011). This process is also inefficient. Of the produced research evidence, only about 14% of findings are implemented into practice (Westfall et al., 2007), leading to unnecessary harm from inefficient practices (Grimshaw et al., 2012; Grol & Wensing, 2013). There are many challenges in implementing evidence into practice, including volume of evidence produced, time to read and skills required to interpret scientific articles, and access to research evidence (Dew & Boydell, 2017; Grimshaw et al., 2012). This supports the need for research examining the gap between research evidence and practice. Reducing the knowledge gap, known as the know-do-gap (Graham et al., 2007), will lead to better outcomes for healthcare and community-based settings.

This process of moving research evidence into practice has many names, including knowledge translation (KT), knowledge mobilization (KM), research utilization, knowledge transfer, knowledge exchange, dissemination, and implementation science (Wathen & MacMillan, 2018). The terminology used will vary according to the setting and the country in which knowledge translation takes place. KT and KM are commonly used in Canada and the United States (Lavis, 2004), whereas implementation science is more often used in England

(Greenhalgh et al., 2004). In Canada, the context in which this project takes place, KT and KM are both umbrella terms ‘encompassing a wide range of activities relating to the production and use of research results, including knowledge synthesis, dissemination, transfer, exchange, and co-creation or co-production by researchers and knowledge users’ (Social Sciences and Humanities Research Council, 2019). The multiplicity of terms and overlapping definitions poses additional challenges for KT researchers (Graham et al., 2006; Grimshaw et al., 2012). In the following section, we provide definitions of the main types of KT used in Canada.

Knowledge Translation

Researchers may address the know-do-gap by implementing an interactive process of knowledge exchange between researchers and those who will benefit from this knowledge. The Canadian Institute of Health Research defines KT as "a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health status, provide more effective health services and products, and strengthen the healthcare system" (CIHR, 2012). It is the concept of using research findings or knowledge to improve policies and practices in applied settings and change population outcomes (Graham et al., 2007; Graham et al., 2006; Levin, 2008; Straus et al., 2011), in other words, educating knowledge users (e.g., policy/decision-makers, service providers, and the general population) on research findings relevant to them and supporting them in using these findings in practice (Canadian Institutes of Health Research, 2015; Graham & Tetroe, 2009).

The typical activities of KT are defined as follows. KT begins with knowledge synthesis, the synthesis and critique of knowledge on a topic (Graham & Tetroe, 2009; Straus & Leung, 2010). It is the contextualization and integration of research findings "within the larger body of knowledge on the topic", including methods such as systematic reviews, narrative syntheses, or

scoping reviews (Canadian Institutes of Health Research, 2010a). The following step is knowledge dissemination or transfer. These two terms traditionally referred to the passive unidirectional and linear process of sharing research findings to an audience (Landry et al., 2001). It is now conceptualized as an active process that involves targeting the appropriate audience and tailoring messages to increase the accessibility of the information for those who will benefit from the knowledge (i.e., knowledge users) (Canadian Institutes of Health Research, 2010b; Graham et al., 2006; Grimshaw et al., 2012). This activity traditionally took place at the end of the process once findings are ready to share with knowledge users. Next, knowledge exchange involves the interaction of researchers and knowledge users, resulting in mutual learning (Canadian Institutes of Health Research, 2015). Finally, this collaboration leads to increased use of findings to change existing practices or implement empirically-based practices (Choi et al., 2005; Graham et al., 2006; Lavis et al., 2005). An advancement in KT may arise from contextualizing findings to a specific setting by including the diverse views from policy-makers, the community, and other key stakeholders (Kothari & Armstrong, 2011).

Integrated Knowledge Translation

More researchers recognize the importance of involving knowledge users throughout the research process (Graham et al., 2018) rather than near the end of the KT. It is argued that knowledge creation contributes to the know-do-gap (Bowen & Graham, 2013; Van De Ven & Johnson, 2006). Our understanding of knowledge may change through increased partnerships between knowledge users and researchers (Jull et al., 2017). Additionally, a more collaborative approach to KT may support the rapid uptake of research evidence leading to a greater impact on policy, practice, and society (Gagliardi et al., 2016; Jull et al., 2017).

This collaborative approach to KT, known as integrated knowledge translation (IKT), goes a step beyond traditional KT by engaging knowledge users in the research process as early as the development of research questions (Graham et al., 2018). IKT is "a model of collaborative research, where researchers work with knowledge users who identify a problem and have the authority to implement the research recommendations" (Kothari et al., 2017). Furthermore, it shifts the traditional role of researchers as sole experts to a balance between the researchers and knowledge-users (Davies et al., 2008). Finally, IKT furthers the relevance, applicability, and impact of implemented practices (Graham et al., 2014; Kothari et al., 2017).

There are minimal differences between IKT and other collaborative research approaches (Nguyen et al., 2020). Participatory research or KM emphasizes the importance of involving knowledge users in the research process. Differences are in power sharing, overall aims and the roles of knowledge users in the research process. In IKT, participating stakeholders have equal roles and authority in the research process. Participatory research also aims for equal roles in research; however, this is achieved through empowering and building on the capacity of collaborators to participate in the research process. KM is quite different as it shifts power dynamics in the opposite direction of traditional KT by giving more power to knowledge users to improve existing services (Nguyen et al., 2020).

In IKT and participatory research, the roles of knowledge users are clearly defined in the research process, whereas their engagement and contribution to knowledge in KM are vague (Fulford & Cobigo, 2020). As for their aims, IKT emphasizes implementing change through collaboration to address problems identified by knowledge users (Canadian Institutes of Health Research, 2015). Participatory research has underlying principles of social justice and social change (Friere, 2000; Lewin, 1946; Nast, 1994). KM focuses on the interactions of knowledge

users and the impact of knowledge-sharing activities (Fulford & Cobigo, 2020). Finally, participatory research and KM are commonly used in social sciences and humanities research, whereas IKT is generally used in medicine and sciences. However, over the past decade, IKT has been used in various non-health-related research, including engineering, environmental science, and technology development (Nguyen et al., 2020).

Theories and Conceptual Models for Implementation of Change

Several theories and conceptual models were developed to guide KT research (Estabrooks et al., 2006; Grol, Wensing, et al., 2013). They provide opportunities to identify implementation barriers and facilitators and support our understanding of varying intervention effectiveness (Graham et al., 2007; Graham & Tetroe, 2009; Nilsen, 2015; The Improved Clinical Effectiveness through Behavioural Research Group, 2006).

Process models describe and guide the KT process by outlining critical components of KT and the steps to successfully implement change (Graham et al., 2007; Nilsen, 2015). These include planning, organizing, and scheduling activities and how the target group may influence these activities (Rossi et al., 1999). Although various models and theories exist, there are similarities between KT theories that can inform KT activities to translate research evidence into practice and policy change (Grol & Wensing, 2013). These step-by-step processes include synthesis and critique of knowledge, knowledge dissemination to knowledge users, and collaboration between researchers and knowledge users to implement evidence-based practices (Choi et al., 2005; Graham et al., 2006; Lavis et al., 2005; Straus & Leung, 2010). Specifically, a review by Grol and colleagues (2013) identified 14 standard components:

1. Systematic approach: sound planning of the implementation activities.

2. The context of change: a solid organization and creation of the context for the process of change.
3. A stepwise process: undertaking a sequenced, logical process leading to the implementation of the plan and its impact on target groups.
4. Evidence for the innovation: sound evidence supporting innovation, attractive presentation.
5. Analysis of performance: mapping actual performance and use of the proposed innovation or new practice by target groups.
6. Diagnostic analysis: a study of the target group and setting before the start of the implementation.
7. Segmentation of the target group: consideration of different stages of the change process and different needs of subgroups.
8. Engagement of the target group in the development, adaptation, and planning of innovation.
9. Alignment: matching the choice of implementation activities to the results of the diagnostic analysis.
10. Multiple intervention planning: consideration of multiple strategies in the intervention, aiming for a cost-effective mix of methods tailored to the obstacles and incentives to change identified.
11. Implementation staging: distinguishing between the phases of implementation (dissemination, implementation, integration); different measures and strategies are effective at different stages.

12. The level of change: take the correct measure at various levels, i.e. national, local, team, practice, and professional.
13. Sustainable change: integrating the implementation strategies into existing routines and structures.
14. Continuous evaluation: ongoing assessment of the impact of the implementation process and its result.

Grol et al. (2013) critically reviewed and evaluated existing literature on KT to develop their Implementation of Change model (see Figure 1.1). Models which combine multiple KT models and frameworks are known to be more effective at changing practices (World Health Organization, 2011). For this reason, we chose the Grol & Wensing Implementation of Change model (2013) to guide our intervention. This model also provides a detailed description of each step of implementing change and how these methods may lead to effective implementation of change (Grol, Wensing, et al., 2013). Furthermore, this model includes the evaluation of the KT process. This is an important step to understand the underlying principles of KT and the feasibility and fidelity of the KT intervention (Hulscher et al., 2013). Finally, the Implementation of Change model (Grol & Wensing, 2013) was created to improve care in the healthcare sector, and we intended to build from this strong expertise in KT to implement change successfully.

The Grol and Wensing Implementation of Change Model (2013) includes seven steps. In this first step, researchers identify evidence relevant for implementing new practices, procedures, techniques, or guidelines. Second, existing practices from the target for implementation are assessed and compared to the evidence identified in the previous step. Next is the analysis of the context in which implementation will occur, including identifying characteristics of the knowledge users and potential implementation considerations. The fourth step consists of

combining knowledge from previous steps to develop or select a strategy for implementation. In step five, researchers collaborate with knowledge users to develop and execute an implementation plan. Step six focuses on the sustainability of the change to prevent relapse. The final step is the ongoing evaluation of the KT intervention, specifically identifying barriers and facilitators that may improve the previous model steps and outcomes.

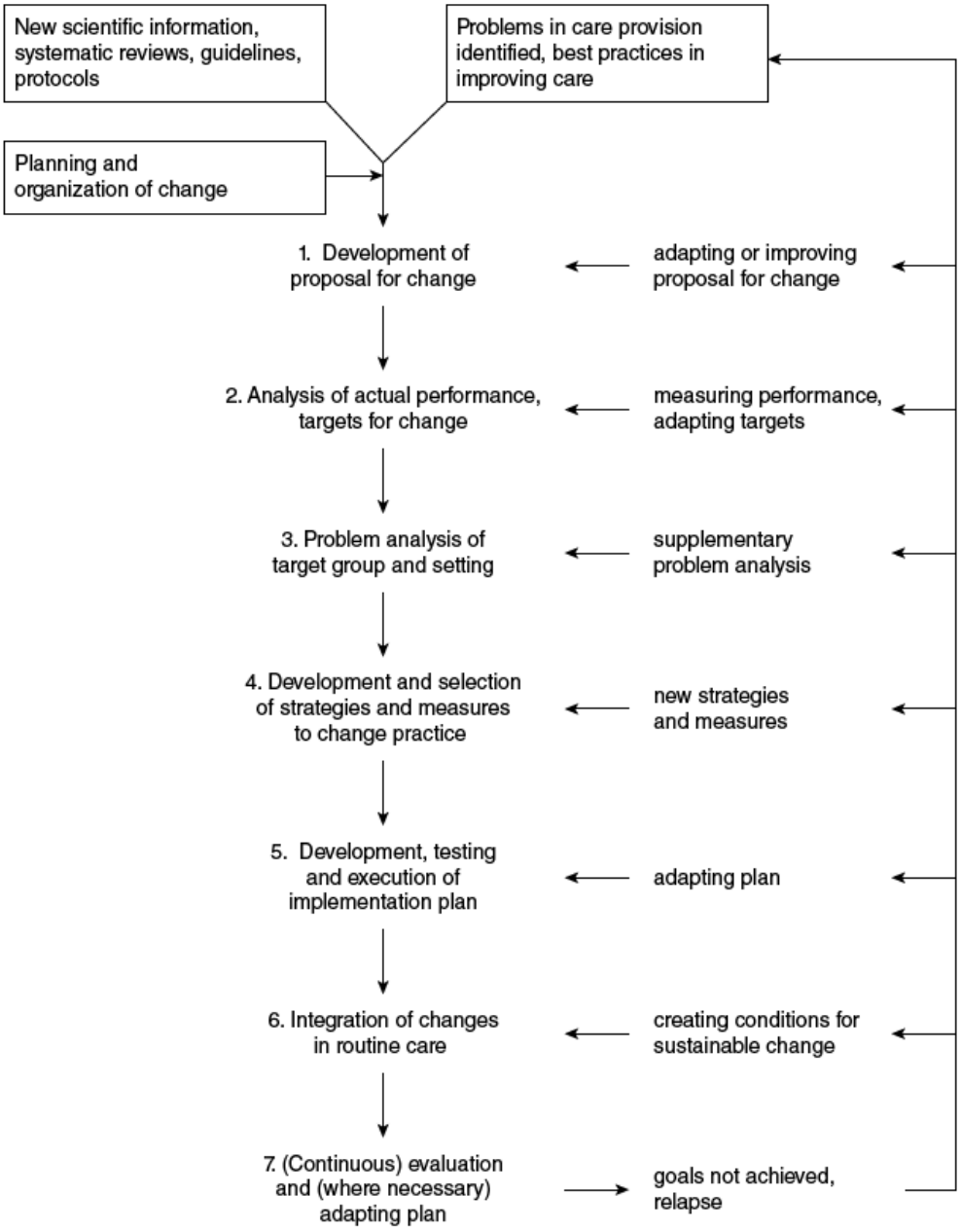


Figure 1.1 The Grol and Wensing Implementation of Change Model. Reprinted from Grol & Wensing (2013, p. 46). Used with permission.

Evaluation of Conceptual Models for KT

Although various models exist and highlight the critical steps to knowledge translation, very little is known about the underlying processes to KT (Kothari & Wathen, 2012; Lillehagen et al., 2016). This lack of understanding of the KT process and components may be explained by the multiplicity of terms and overlapping definitions of KT (Graham et al., 2006; Grimshaw et al., 2012). Furthermore, previous research has focused on the importance of evidence-based practice rather than the process of implementing change (Singh, 2016). Furthermore, there is a lack of evidence to support which KT activities work within a given context (Mitton et al., 2007). Researchers call for additional studies on the underlying processes of KT to understand how knowledge becomes translated (Greenhalgh & Wieringa, 2011; Kitto et al., 2012) and to identify which strategies are more effective in a specific context (Mitton et al., 2007). Evaluation is essential to ensure that valid and reliable knowledge is integrated into practice (Graham et al., 2007). Understanding the process of implementing a KT model would provide information about the utility of the model in leading to change (Graham et al., 2007), and justify the effort and resources devoted to developing KT models (Lillehagen et al., 2016).

Types of Evaluation. There are two main approaches for the evaluation of interventions: summative and formative evaluations. Summative evaluation measures the outcomes and impact of an intervention. They focus on whether interventions meet their expected outcomes by answering questions around the cost and benefits of the intervention and justify the ongoing use or termination of existing interventions. On the other hand, formative evaluations focus on improving the delivery of interventions (Hatry et al., 2015). It does not question the existence of the evaluation; instead, it aims to gather feedback to improve the effectiveness of the intervention.

Process Evaluation. Evaluating the process in which KT informs change in policy and practice would be beneficial (Eagar et al., 2003; Lavis et al., 2003). Process evaluation describes the change as it occurs, whether it was planned, delivered, and led to actual exposure of knowledge users in the intervention, and to understand the experiences of those exposed to the intervention (Hulscher et al., 2013). Additionally, this method supports qualitative (Pope et al., 2002) and quantitative designs, used separately or together throughout the intervention (Hatry et al., 2015). This means that various sources of information are used in process evaluation, including observations, self-report through interviews, focus groups or questionnaires, and analysis of existing records (Hulscher et al., 2013). This method can identify which processes or mechanisms are related to the lack of uptake of research evidence in practice. Given our lack of understanding of KT processes successful in applied settings (e.g., community) (Graham et al., 2007; Grimshaw et al., 2012; Mitton et al., 2007; Straus et al., 2011), it is essential to conduct process evaluations in these settings. These findings would inform researchers of improved methods to implement KT activities in the community (Aaserud et al., 2005).

KT in Community-based Settings

Most KT research relates to medical decision-making and improving patient care in the private and healthcare sector (Levin, 2008); however, KT has also been used in other areas, including the social and community sectors (Goldner et al., 2011). Community settings typically engage in collaborative research such as participatory research. KT is embedded in this approach; however, the focus is on knowledge utilization leading to equity in social justice (Nguyen et al., 2020). Little is known about the effectiveness of KT strategies in community-based organizations (Wilson et al., 2010). As the environment between community and healthcare sectors differ, so may the KT processes and strategies (Contandriopoulos et al., 2010;

Kothari & Armstrong, 2011). Contandriopoulos et al. (2010) suggest that researchers consider the relevance of using clinical KT strategies in community-based settings. For example, collaboration among various stakeholders may prove more critical in community-based settings (e.g., service agencies), where collaboration is prioritized in decision-making processes (Kothari & Armstrong, 2011). There is limited research on this process of negotiating and collaborating to co-create knowledge (Kothari & Wathen, 2012).

There is an abundance of research on developing KT models and frameworks in the healthcare sector; however, little attention has been given to these in community-based settings (Lencucha et al., 2010; Wilson et al., 2010). By engaging community-based organizations in IKT, we could improve our understanding of how knowledge users collaborate to create and use knowledge and the impact of KT interventions in this setting (Graham & Tetroe, 2007).

The Case for IKT in Intellectual Disability Research

IKT is particularly interesting in intellectual disability research. Persons with intellectual disabilities represent a group that has been historically excluded from research (Feldman et al., 2014; Gibbs et al., 2008) due to challenges with recruitment, obtaining consent and assent, and ethical concerns around their vulnerability to abuse and exploitation (Cox et al., 2019). However, by excluding persons with ID from research, we lose access to essential knowledge on their lived experiences that may increase the relevance of research outcomes and outputs targeting persons with ID (Aman & Handen, 2006; McDonald et al., 2013; McVilly & Dalton, 2006).

There is a lack of research on KT involving persons with intellectual disabilities (Martin et al., 2010; Shooshtari et al., 2014). Of the research focused on persons with intellectual disabilities, KT research focuses on healthcare practices (Martin et al., 2010; Shooshtari et al.,

2014; Spassiani et al., 2016). Previous studies have identified barriers to KT research involving persons with intellectual disabilities. These include a lack of time, financial, and organizational support to engage in KT over a long period (Martin et al., 2010; Shooshtari et al., 2014). Additionally, not prioritizing research use, policies, and a lack of accessible research material in an appropriate language were barriers to KT for persons with intellectual disabilities (Martin et al., 2010; Shooshtari et al., 2014). Findings from these studies may not apply to community-based organizations, where persons with intellectual disabilities receive support for many aspects of their daily lives (e.g., residential, leisure, and employment support).

IKT may address challenges in including persons with intellectual disabilities in KT research. By being embedded in the collaboration between research and knowledge users throughout the research process, IKT facilitates the inclusion of persons with intellectual disabilities. It provides opportunities for persons with intellectual disabilities to engage actively in and modify the research process. Furthermore, by allowing flexibility in research methods throughout the process, IKT is more accessible to persons with intellectual disabilities (Dorozenko et al., 2016). A previous study identified increased exchanges with stakeholders, working with community organizations, and having more accessible research as facilitators to KT with persons with ID (Shooshtari et al., 2014). Furthermore, the involvement of persons with intellectual disabilities and their support staff in IKT may provide them with the necessary skills to engage in research (Spassiani et al., 2016). By increasing IKT research in the community-based setting, KT interventions may lead to policy and practice changes that better support persons with intellectual disabilities (Martin et al., 2010).

Description of Population. The three criteria for identification and classification of intellectual disability (ID) consist of significant limitations in intellectual functioning, significant

limitations in adaptive behaviours, and originates before 18 years of age (American Association on Intellectual and Developmental Disabilities, 2013). Deficits in intellectual functioning include difficulties in planning, abstract thinking, problem-solving, and reasoning. One way to measure intellectual functioning is with an Intelligence Quotient (IQ) test, where an IQ score below 70 would indicate significant limitations in this domain (American Association on Intellectual and Developmental Disabilities, 2013). Adaptive behaviour refers to the ability to meet the standards of independence and responsibility at both the developmental and sociocultural levels (American Psychiatric Association, 2013). This includes three types of skills: conceptual skills, such as literacy and numeracy; social skills, including interpersonal skills and ability to follow the rules; and practical skills, such as activities of daily living and occupational skills (American Association on Intellectual and Developmental Disabilities, 2013). Intellectual disability may also vary in level of severity (mild, moderate, severe, and profound) (American Psychiatric Association, 2013).

History of Sexual Rights. Persons with ID represent a group who should have equal opportunities to have fulfilling sexual lives and reciprocal relationships within their communities (United Nations, 2006). Sexuality plays a vital role in the lives of human beings. Sexuality encompasses "sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships" (World Health Organization, 2015). Furthermore, sexuality is multidimensional; it includes biological, psychological, social, cultural, religious, and spiritual factors (World Health Organization, 2015). For the context of this study, it is also important to establish the differences between sexual desires and sexual activity. Sexual desires are a "desire for sexual pleasure, and sexual activity is an activity which

tends to, and is intended to, arouse or fulfill such desire of the agent or of someone else" (Spiecker & Steutel, 2002). The fulfillment of these desires is related to one's well-being and physical health (Weijmar Schultz & van de Wiel, 2003). In addition to benefits for the population at large, sexuality plays an integral part in normalizing the experiences of people with intellectual disabilities. However, sexuality has been historically contested for people with ID (Rose & Rennie, 2007).

In 1876, the first large institution for persons with intellectual disabilities, the Ontario Asylum for Idiots, was opened in Ontario (Brown & Percy, 2003). In the 1970s, there were approximately 30 institutions for people with ID in Ontario (Brown & Percy, 2003). It is not until 1974, when Ontario passed the *Developmental Services Act,* that the responsibility for services for people with ID shifted from the Ministry of Health to the Ministry of Community and Social Services; thus, from a medical to a community perspective (Ministry of Community and Social Services, 2012). Despite legislation for the social inclusion of people with ID, there were still a total of 3,873 individuals living in institutions across Canada in 2006 (Institution Watch, 2006). In 2008, Ontario enacted the *Service and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* ("*Social Inclusion Act*") to replace the *Developmental Services Act* (Ministry of Community and Social Services, 2008). These efforts were intended to shift services for people with ID from institutionalized to community-based care by providing better services closer to home, more choices, and control over the services individuals with ID receive. In March 2009, the last government-operated institution in Ontario was closed (Ministry of Community and Social Services, 2012). With this shift came substantial changes in community attitudes towards this group and a reinforcement of their rights. This included significant legislative reform for the sexual rights of persons with ID. At the

international level, the *United Nations Standard Rules on Equalization of Opportunities* (Rule 9), introduced in 1993, stated that people with disabilities 'must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood' (United Nations, 1993). In 2006, the United Nations enacted the *Convention on Rights of Persons with Disabilities* (2006), specifying that people with disabilities have the right to marry, to found a family and retain their fertility (Article 23); and have access to sexual and reproductive health care (Article 25) (United Nations, 2006). In 2017, the Government of Canada tabled the *Optional Protocol* to the United Nations *Convention on the Rights of Persons with Disabilities,* which allows Canadians to submit a complaint to the United Nations if their rights under this convention are violated (Employment and Social Development Canada, 2017). Persons with ID have the right to express their sexuality and choose their experiences without being precluded from a fulfilling sexual life (Smyth & Bell, 2006).

Supporting the Sexuality of Persons with ID. Adults with ID may require support in all facets of their daily lives. In Canada, adults with ID may apply for community-based services. These community-based services are governed by service agencies that provide leisure, residential, employment, and educational support services. Service agencies aim to support persons with ID by providing them with opportunities to live in more inclusive environments (Bellamy et al., 1990) and to enjoy reciprocal relationships, including sexual relationships (Lofgren-Martenson, 2004). Staff working in service agencies directly influence how sexual knowledge is provided and how people with ID view their sexuality (Eagly & Chaiken, 2007; Evans et al., 2009; Wilkinson et al., 2015). For example, front-line staff attitudes, which are often influenced by their values, beliefs, and experiences towards the sexuality of adults with ID, may be reflected through the omission of discussing specific topics such as masturbation, diverse

sexual practices, and even topics on same-sex sexual activities and relationships (Stinson et al., 2002).

Service providers often do not feel at ease discussing sexuality (Haboubi & Lincoln, 2003; Rushbrooke et al., 2014; Young et al., 2012). Discomfort among staff may lead to inadequate sex education and deprive adults with ID of equal opportunities to have the sexual life of their choice (Galea et al., 2004; Murphy & O'Callaghan, 2004; Servais, 2006). This may, in turn, increase the risks of sexual abuse and exploitation of adults with ID, as well as the risk of sexually transmitted infections and unwanted pregnancies (Ailey et al., 2003). Staff also report concerns with unsupervised relationships between adults with ID at their service agencies (Evans et al., 2009). Finally, a lack of confidence in their abilities to support the sexuality and relationships of persons with ID has been reported (Abbott & Howarth, 2007).

Discomfort and low confidence may be reflected from insufficient training and an absence of resources available to service providers to discuss and support the sexual experiences of adults with ID (Evans et al., 2009; Swango-Wilson, 2008; Wilkinson et al., 2015). A study by Evans (2009) with 381 staff participating revealed that only 12% had received training in sexuality, whereas in McConkey and Ryan's study (2001) with 150 participants, 20% of staff had received training. When asked which option would make staff more confident in dealing with the sexuality of adults with ID, 46% of staff opted for more training (McConkey & Ryan, 2001). Service providers call for training; however, they specified that training should be supported by supervision procedures and organizational policies (Lafferty et al., 2012). Service providers require training to maintain appropriate sexual behaviour (Rushbrooke et al., 2014), which would allow greater privacy and sexual autonomy for adults with ID (Evans et al., 2009). In addition, service agencies lack clear policies on how support should be provided and how the

sexual expression of people with ID can be developed (Stinson et al., 2002). Although service providers are divided on how to approach sexuality, they agree that sexuality is a major concern among this population and want tools and resources to support the sexuality of persons with ID (Evans et al., 2009; Wilkinson et al., 2015).

IKT and Supporting Sexuality of Persons with ID. KT research should focus on topics relevant to various stakeholders (i.e., persons with ID, agency personnel, and caregivers) (Shooshtari et al., 2014) to encourage engagement in the process. Supporting sexuality in community-based settings is one topic of the utmost importance for various stakeholders. Caregivers and service providers call for additional tools and resources to support the sexuality of persons with ID (Evans et al., 2009; Swango-Wilson, 2008; Wilkinson et al., 2015). Although persons with ID receive support from community-based organizations, this support is insufficient to promote sexual autonomy and increase sexual knowledge and social skills (Evans et al., 2009; Swango-Wilson, 2008; Wilkinson et al., 2015). Additionally, persons with ID may not experience the same opportunities and sexual freedoms as those without ID (Cox et al., 2019).

Strategies to further support the sexuality of persons with ID could be implemented in community-based organizations. However, additional research is required to identify what this support should be (Chrastina & Večeřová, 2020). The involvement of various stakeholders in the implementation process may be a first step in the right direction (Hale et al., 2011). This should involve identifying knowledge on the preferences of persons with ID and potential contextual barriers to appropriately tailor interventions for persons with ID (Bartholomew et al., 2011; Kuijken et al., 2016). Researchers can identify this knowledge by collaborating with community members using IKT. Through IKT, research may more accurately reflect the lived experiences of persons with ID (Kothari & Wathen, 2012; Spassiani et al., 2016), and interventions become

more readily accepted (Harrison et al., 2010). Finally, researchers need to continue evaluating KT processes to appropriately leverage the expertise of persons with ID (Martin et al., 2010). The evaluation of IKT may inform practice and policy changes that further support the sexuality of persons with ID.

Study Objectives

There are currently no studies on supporting the sexuality of persons with ID that have evaluated the translation of evidence into practice change in community-based organizations. Therefore, the objectives of this project were to 1) develop and implement an IKT intervention to support the sexuality of persons with ID, and 2) evaluate the use of the Grol & Wensing's Implementation of Change Model (2013) in guiding this intervention in a not-for-profit, community-based organization in Ontario, Canada. The project addressed the following three evaluation questions:

1) Were the steps of the IKT intervention completed as intended?

2) What were the facilitators and barriers of the IKT intervention, as perceived by the stakeholders involved?

3) What were the decision-making processes, how were decisions made, and how did this further the IKT process?

Chapter 2 – Overview of the Research Methods

This chapter provides the context of the study, an overview of the study steps according to the Grol and Wensing's Implementation of Change Model (2013), and a detailed description of the research methods. These details cover the research design, procedures, and ethical considerations.

Study Context

One community-based service agency participated in the study. This agency, the *Association pour l'intégration sociale d'Ottawa* (AISO), was founded in 1991. Its mission is to provide francophone services to persons with ID that promote self-development and community inclusion. The AISO supports 273 persons with ID and relies on 150 employees and occasional volunteers. Employees involve front-line staff, supervisors, administrative team, and senior management. Employees may also be persons with ID currently receiving services. This agency also supports an independent advocacy group led by and for persons with ID, the *Mouvement des personnes d'abord d'Ottawa*.

The AISO is the only service agency in Ontario that offers services to persons with ID exclusively in French. Services provided include residential, leisure, adult support, and employment services to adults with ID in Ottawa. Residential services consist of 8 different group homes near community services and resources in different areas of Ottawa. These group homes have a 5-person maximum capacity and allow residents to participate in community activities alone or with their roommates.

Persons with ID receiving residential services have high support needs. For this reason, front-line staff working in these homes are present 24 hours a day to provide individualized support. Front-line staff will also accompany persons with ID to day programs and outings to public services (e.g., pool, gym, mall, restaurants, library). Another relevant service for this study is adult support services. These services are intended to support persons with ID with low support needs in 3 different scenarios: 1) for persons with ID and their families currently residing together, 2) for persons with ID living independently in apartments, and 3) for shared homes (*foyer-partage*). Support for persons with ID and their families involves planning, orientation,

access to services, and technical services such as completing intake forms, applying for grants, and clinical services. For persons with ID receiving support in apartment living, front-line staff would assist planning, accompaniment, and service support (e.g., medical appointments and shopping), as well as the technical services mentioned previously and budget management. Unlike residential services, support staff involvement varies across individuals, from a few hours of support weekly or monthly. For those living in apartments that require support to transition to more independent living, front-line staff may have increased involvement to ensure a balanced or specific diet, assist with medication intake, safety, security, and prevent instances of crisis or abuse. Finally, shared-home (*foyer-partage*) services are cohabitation between caregivers (that are not family members) and persons with ID. These caregivers may be individuals, couples, or families interested in supporting a person or persons with ID. Eligible caregivers must meet essential requirements such as speaking primarily in French at home and have specific competencies such as encouraging choice, supporting autonomy, and respecting identity. Multiple meetings between the caregivers and the persons with ID will take place to establish the best match. Much like other services provided by the AISO, shared-home services focus on personal development, establishing relationships and complete social integration of persons with ID.

The site had previously collaborated with the research team. Familiarity with the research team was crucial as service providers may be reluctant to participate in research. Established rapport may reduce anxiety (d'Abrera et al., 2013) and service agencies may be more inclined to help recruit potential participants following previous positive research experiences. Research has also shown that persons with ID are more inclined to participate in a study if familiarity with the researcher is established (Nicholson et al., 2013). Focus groups occurred at the service agency to

maintain a familiar setting for participants and reduce distractions (Boyden et al., 2009). Finally, citations are presented in the participant's chosen language (French) throughout the dissertation to respect the original meaning. French citations are paraphrased in English.

Overview

We structured the project around the seven steps of Grol and Wensing's Implementation of Change Model (2013) (see Figure 1.1). For ease of reporting, the research methods for each of the seven steps of the model are presented separately; however, study activities did overlap as we conducted a process evaluation in parallel with study interventions. We developed a logic model of the intended IKT intervention to map out the different study steps and their relation (view Figure 2.1).

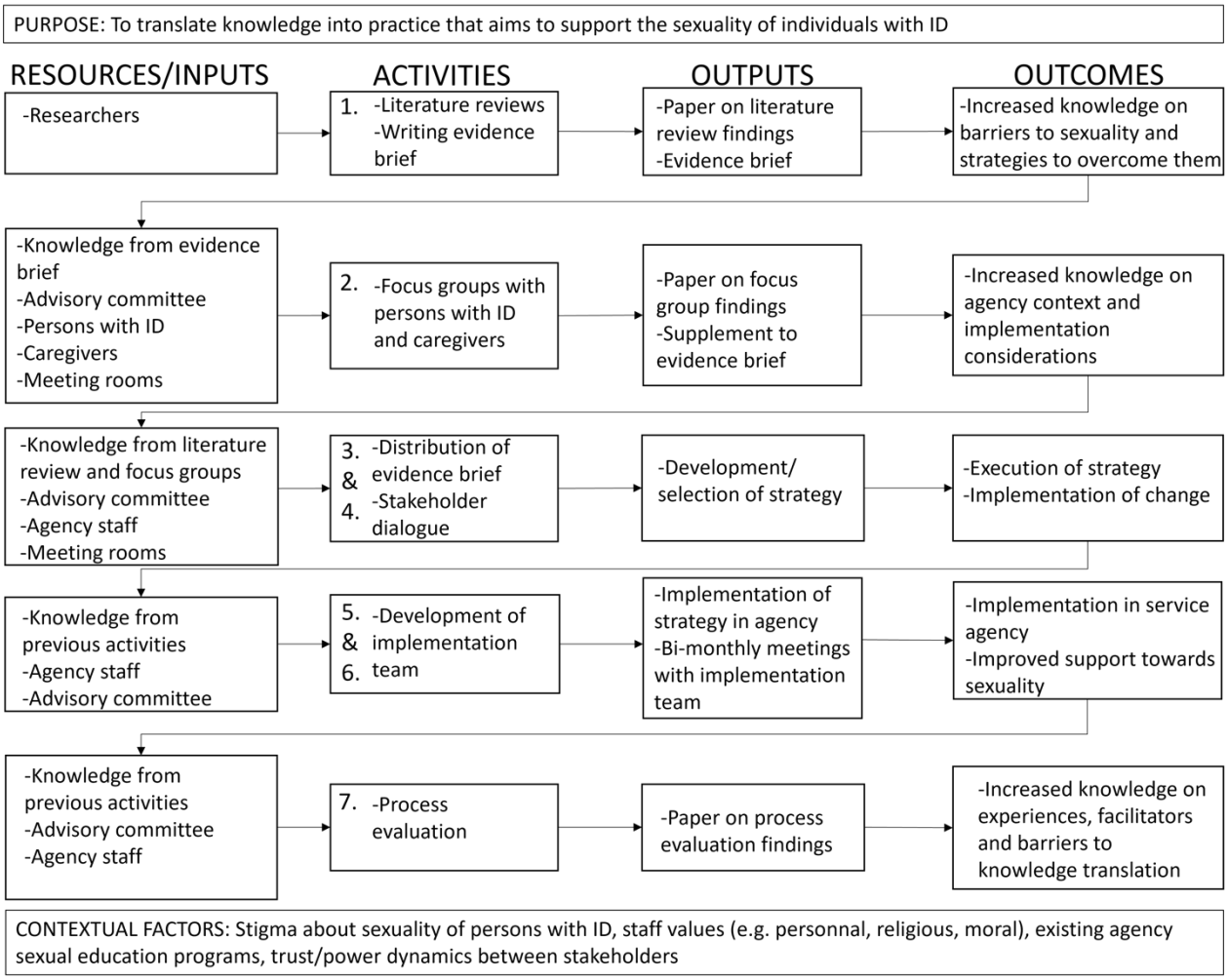


Figure 2.1 Logic model describing the intended integrated knowledge translation intervention

We begin this section by presenting an overview of the seven steps of the Grol and Wensing model (2013), followed by the detailed procedure of each step.

1) Development of a proposal for change. We conducted a literature review to identify strategies and implementation considerations for supporting the sexuality of adults with ID.
2) Analysis of actual performance. We conducted focus groups with persons with ID, agency personnel and family caregivers to explore the quality of support received and suggestions for improvements.

3 & 4) Problem analysis and selection of strategies to change practices. We developed an evidence brief containing the findings of the literature review and focus groups. This document supported a stakeholder dialogue led by the primary researcher in the participating agency to explore foreseeable determinants of change.

5 & 6) Development and execution of a strategy. The participating agency created an implementation team to develop and implement a strategy chosen from the stakeholder dialogue. This involved hiring a person with ID to develop and facilitate two sexual education workshops.

7) Evaluation of the implementation process. We conducted a process evaluation to examine the delivery of and to describe the experiences of those exposed to the KT intervention.

Ethics

The research team obtained ethics approval from the University of Ottawa's Health Sciences and Science Research Ethics Board (REB file # H09-16-08).

Advisory Committee

An advisory committee supported the primary researcher, consisting of front-line staff and management from the agency's two primary services relevant to the study: residential services and support services for adults. This committee informed the study direction, led participant recruitment, and provided facilities for research activities. Furthermore, they collected consent forms, demographic information (e.g., age, gender, service agency they attend, how long they have attended) and contact information for study participants. The advisory committee contacted the primary researcher to schedule study activities once participants were confirmed.

Design per Study Step

1 – Development of a Proposal for Change. The first step of the Implementation of Change model (Grol, Wensing, et al., 2013) includes using scientific information to develop a feasible proposal for change. This involves identifying best practices to address a target issue and extracting and synthesizing relevant information for key stakeholders to make informed decisions.

In the context of this study, we synthesized and appraised previous research on promising and best practices to support the sexuality of adults with ID. We established the current state of knowledge on possible interventions and implementation considerations to address barriers towards the sexuality of persons with ID. In the first step of the Implementation of Change Model (Grol, Ouwens, et al., 2013), it is essential to discuss the credibility and quality of interventions. Thus, in addition to identifying interventions in the scoping review, we determined the level of evidence supporting them.

The knowledge identified at this step was the foundation of future study activities. It informed various stakeholders of existing interventions, supporting evidence, and considerations for their implementation. Chapter 3, Section 1 provides additional information on the scoping review and quality assessment method.

2 – Analysis of Actual Performance. Following the development of a proposal for change, current practices were reviewed and assessed to determine the most significant deviations from best practices.

We conducted focus groups with key stakeholders to establish existing supports towards the sexuality of persons with ID, present scoping review findings, and discuss implementation considerations. The stakeholders included front-line staff, persons with ID, and caregivers. Through these focus groups with relevant stakeholders, the primary researcher understood the setting in which the IKT intervention took place. Furthermore, we identified preferences for strategies to support sexuality and additional implementation considerations.

This knowledge informed decision-making in the following study step. See Chapter 3, Section 2 for additional information on focus group participants and procedures.

3 & 4 – Problem analysis and selection of strategies to change practices. It was essential to consolidate multiple sources of information to understand the context to address a target issue.

A detailed document called an evidence brief was created to inform decision-making on which strategy or strategies to implement at the target service agency. This brief contained a short review of key issues around supporting the sexuality of persons with ID. This was followed by a description of the strategies identified in the scoping review, their quality assessment results, and potential limitations. Finally, the brief incorporated focus group findings on existing

supports, improvements that could be made, and on implementation considerations for each stakeholder group. The evidence brief supported a large group discussion, known as a stakeholder dialogue, with persons with ID, caregivers, front-line staff, supervisors, and upper management (e.g., directors).

In this step, we gained a better understanding of the feasibility of implementing different strategies and insight from stakeholders with different perspectives and expertise on the issue. The dialogue led to the development of the implementation team for the following study step. In Chapter 3, Section 2, we provide information on the development and use of the evidence brief in the stakeholder dialogue.

5 & 6 − Development and Implementation of a Strategy. The implementation team, consisting of advisory committee members and two persons with ID, developed the implementation plan and was tasked with integrating changes into routine practices.

The team decided that two workshops for sexual education would be the best fit. These workshops were developed by the primary researcher and informed by consultations with relevant stakeholders, collaboration with a person with ID (co-researcher[2]) currently receiving services from the agency, and reviews of credible sources. Workshops were administered one week apart on two separate but related topics: the first on sexual diversity and the second on protection methods. Workshops were designed for both persons with ID and front-line staff to attend together and sequentially. Finally, the primary researcher and the co-researcher administered the workshops. See Chapter 3, Section 2 for additional information on the implementation of two workshops.

[2] Co-researcher was hired as a member of the research team to co-develop and co-facilitate the sexual education workshops.

7 − Process Evaluation. The last step of the Grol and Wensing (2013) Implementation of Change Model includes a process evaluation. In this study, process evaluation identified barriers and facilitators to conducting IKT. The overarching questions for the evaluation were:

1) Were the steps of the IKT intervention completed as intended?

2) What were the facilitators and barriers of the IKT intervention, as perceived by the stakeholders involved?

3) What were the decision-making processes, how were decisions made, and how did this further the IKT process?

All study documentation was subject to evaluation, such as the evidence brief, transcriptions from focus groups, the stakeholder dialogue and the workshops, and all notes taken by the research team. Self-reported questionnaires were also administered following the stakeholder dialogue and each workshop. Finally, after the study, an undergraduate student[3] completed two separate semi-structured interviews with the primary researcher and the adult with ID who facilitated the workshops. These interviews sought to gather feedback on the experiences of working collaboratively in developing and implementing the sexual education workshops. All sources of data were analyzed using thematic analysis.

This project activity identified key barriers and facilitators to conducting IKT with persons with ID in a community-based service agency. This also informed the development of the final research output: an online, facilitator-free version of the sexual education program for persons with ID and front-line staff. There is additional information on the process evaluation in Chapter 4.

[3] This undergraduate student (DL) completed the interviews as part of an honours thesis in psychology.

Chapter 3 – IKT Intervention for Supporting the Sexuality of Persons with ID in a Community-Based Service Agency

The dissertation had two main aims: 1) to conduct an IKT intervention supporting the sexuality of persons with ID, and 2) to evaluate this intervention. Chapter 3 focuses on the first aim: describing the IKT intervention. This represents the first six steps of the Implementation of Change model by Grol & Wensing (2013), from knowledge identification to implementing the chosen intervention.

This chapter is divided into two sections. Section 1 identifies the research knowledge to translate using a scoping review. Section 2 examines how the knowledge identified in Section 1 may be tailored and how stakeholders implemented change within a community-based service agency. We conclude Section 2 with a general discussion on the findings of the integrated knowledge translation intervention.

Section 1. Identifying the Knowledge to Translate

Once the primary researcher established a logic model for the intended steps of the IKT intervention, the next step was to identify the knowledge to translate. Using a scoping review, we identified strategies with the highest level of evidence to support the sexuality of persons with ID.

Introduction

Previous studies have shown that sex education may be beneficial to support the sexuality of persons with ID. For example, existing programs on reproductive physiology, communication, gender differences, and safer sex may increase the ability of women with ID to recognize and report abuse (Dukes and McGuire, 2009; Murphy, 2003; Swango-Wilson, 2011). Other sexual education programs may increase the social skills of persons with ID (Hayashi et al., 2011) and their capacity to make sex-related decisions (Dukes & McGuire, 2009). Finally, sexual education programs increase the sexual knowledge of persons with ID (Caspar & Glidden, 2001; Garwood & McCabe, 2000). Although sexual education is promising to support the sexuality of persons with ID, there are many drawbacks with existing programs.

There is little information about the effectiveness of these programs in supporting the sexuality of persons with ID. Previous reviews revealed that sexual education programs for persons with ID lack evaluation and long-term follow-up measures (Grieve et al., 2007; Schaafsma et al., 2013). These programs rarely include persons with ID, program implementers and decision-makers in their development stages (Schaafsma et al., 2013). This may reduce the relevance for the users and reduce the likelihood of successful implementation. They are also limited in their ability to generalize the acquired knowledge or skills into real-life situations

(Blanchett & Wolfe, 2002; Schaafsma et al., 2015). Furthermore, programs are practice rather than theory- or evidence-based (Schaafsma, Stoffelen, Kok, & Curfs, 2013) despite the large body of research showing that practice-based programs are not as effective as theory- and evidence-based programs (Albarracín et al., 2005; Bos et al., 2008; de Bruin et al., 2010; Peters et al., 2009; van Achterberg et al., 2011). Another review by Shaafsma et al. (2015) aimed at identifying effective methods for teaching sexual education to persons with ID. The authors identified 20 different sexual education programs aimed at increasing knowledge or improving skills or attitudes of adults with ID (Schaafsma, et al., 2015). This review revealed a lack of information provided by study authors on the program materials, goals, and the methods used, rendering it challenging to establish the effectiveness of reviewed sexual education programs (Schaafsma et al., 2015).

Existing research also highlights drawbacks with the content of existing sexual education programs. Most programs aim to increase sexual knowledge of persons with ID in areas such as preventing unwanted pregnancies, sexually transmitted infections, and sexual abuse (Conod & Servais, 2008; Schaafsma et al., 2013). Although these are crucial areas in sexual education for persons with ID, the emphasis on increasing knowledge on the protective aspects of sexuality may create an association between sexual experiences and fear of risks, which may hinder the development of intimate relationships and sexual identity (Rushbrooke, Murray, et al., 2014; Stinson et al., 2002; Wilkinson et al., 2015). These programs also promote the sexuality of persons with ID as non-reproductive, solitary, and heterosexually oriented (Cambridge & Mellan, 2000; Gill, 2012) which may impede the sexual exploration and satisfaction of persons with ID (Wilkinson et al., 2015). Finally, sexual education programs for persons with ID are generally unknown or simply not used in practice (Grieve et al., 2007; Plaute et al., 2002).

Currently, sexual education programs may not suffice to support the sexuality of persons with ID.

At the time of the project (2018), we needed an updated review of strategies to support the sexuality of persons with ID. First, the most recent sexual education program included in existing reviews was from 2012 (Schaafsma et al., 2015); however, sexual education programs may evolve to account for societal attitudes and technological advances. Existing reviews have not captured programs developed in the six years prior to the start of this project. Second, existing reviews exploring the effectiveness of sexual education programs have not used validated quality assessment tools to report on the quality of the included articles and provided little information on quality assessment results. Finally, previous reviews focused on sexual education programs as the only method to support the sexuality of persons with ID.

Other strategies to support the sexuality of persons with ID include increasing awareness of the influence service providers have on the sexuality of adults with ID (Rushbrooke et al., 2014; Wilkinson et al., 2015). Furthermore, the implementation of policies within the agency can address challenges such as privacy. A study set in the United Kingdom identified six points to consider for overnight stays in residents' bedrooms: a contractual agreement between the individual and the service provider, the use of an independent advocate, a guide for persons with ID to provide information on the required arrangements to put in place, the role of staff in supporting other persons with ID living there and the person wanting to stay over, and conducting an assessment to establish that it is a consenting relationship (Hollomotz, 2009). Service agencies could have additional policies to respond to challenges in supporting the sexual needs and desires of adults with ID while keeping them safe (Stinson et al., 2002). To further support the sexuality of people with ID, service providers may increase access to sex and

relationship education and remove barriers such as curfews (Wilkinson et al., 2015). Finally, service providers may challenge heterosexism by using LGBTQ images when possible or by including lesbian and gay venues, films, and plays in outings (Howarth & Abbott, 2005).

This review aimed to synthesize and appraise previous research on promising and best practices in supporting the sexuality of adults with ID. Specifically, our primary objectives were to 1) establish the current state of knowledge on possible strategies to support the sexuality of persons with ID, 2) identify related implementation considerations and 3) determine the level of evidence of each strategy. Our goal was to use this knowledge to inform service providers of existing interventions to implement in community-based service agencies.

Method

Scoping literature reviews are typically undertaken to "summarize a range of evidence to convey the breadth and depth of a field" (Levac et al., 2010). For this review, we aimed to gather all strategies to support the sexuality of persons with ID. Finally, although quality assessments are not typically conducted as part of a scoping review (Arksey & O'Malley, 2005; Levac et al., 2010), this step was crucial in answering our review objectives.

Search Strategy and Screening

The search strategy included the OVID (PsycInfo), ProQuest, and Academic Search Complete databases for papers published from 2000 to August 2018. The search was limited to this period to remain relevant with the shift from institutional to community-based care. The search strategy included broad terms related to intellectual disability *("intellectual disability" OR "intellectual disability disorder" OR "developmental disability" OR "mental retardation")*, combined with terms related to sexuality *("sexuality" OR "sex" OR "sexual experiences" OR*

"sexual behaviour" OR "sexual activity" OR "sexual identity" OR "sexual relationships" OR "intimacy"). The search strategy remained broad to capture all types of strategies to support the sexuality of persons with ID. Grey literature was searched using the Google search engine and included search terms related to intellectual disability and sexuality.

The primary researcher (NP) screened the titles for relevance. Relevant titles were selected for abstract review, followed by a full-text review. Included articles were: (1) published in English or French; (2) published between 2000 and 2018; and (3) explored strategies to support the sexuality of adults with ID (using any study design). We excluded articles: (1) when the full text was not available, and (2) if they were literature reviews or book chapters.

Quality Assessment

The primary researcher and an undergraduate psychology student[4] completed the quality assessment of all included articles. We used the Mixed Methods Appraisal Tool (MMAT) to include quantitative, qualitative, and mixed methods studies (Pluye et al., 2011). This tool has been used previously and shown to be a reliable tool for assessing mixed methods reviews (Pace et al., 2011). This checklist consists of two screening questions, followed by four questions assessing study quality per study type (i.e., qualitative, quantitative randomized controlled trials, quantitative non-randomized, quantitative descriptive, and mixed methods). We included articles that were of moderate or high quality (i.e., above 50% criteria). The primary researcher and the undergraduate student independently assessed each paper and resolved disagreements through discussion.

[4] Student received training on completing systematic reviews and on conducting quality assessments.

Data Extraction and Analysis

The primary researcher used summary tables to extract key study elements such as authors, participants, study design, and critical findings. In addition to the quality assessment results, these tables were used to summarize each strategy and determine the level of evidence of potential strategies to address barriers to supporting the sexuality of adults with ID. The level of evidence was established according to the study design (Table 3.1) (Khan et al., 2001). For example, randomized control trials have high evidence quality, whereas observational studies have low evidence quality (Guyatt et al., 2011). The quality of the evidence for each identified strategy in the literature review was rated as high (3), moderate (2), or low (1).

Table 3.1 *Evidence Hierarchy of Study Designs by Khan et al. (2001)*

Hierarchy	Study design
1.	Randomized controlled trials
1a.	Randomized cross-over trials
1b.	Cluster randomized trials
2.	Quasi-experimental studies
2a.	Non-randomized controlled studies
2b.	Before-and-after study
2c.	Interrupted time series
3.	Observational studies
3a.	Cohort study
3b.	Case-control study
3c.	Case series

Results

Search Results

The search identified 629 articles to be screened and assessed for eligibility. A total of 263 duplicates were removed. Of the 366 articles inspected for relevance, 295 articles were removed following title and abstract review. These articles were removed because they were not about supporting the sexuality of persons with ID (*n* = 175), were not in English or French (*n* = 17), were not available (*n* = 16), or were not primary peer-reviewed articles (*n* = 87). Finally, of the 71 articles read in full, 2 were not in French or English, 10 full texts were not available, 11 were reviews or book chapters, and 40 were not related to strategies to support the sexuality of adults with ID. After reviewing the data collection forms, the primary researcher identified 4 articles that met all inclusion criteria (see Figure 3.1). Only two pre-test/post-test studies were included (Table 3.2). The other two studies were qualitative studies using either a group discussion or semi-structured in-depth interviews with direct field observations. Studies were conducted in the United States of America and Australia. Sample sizes ranged from 6 to 35 persons with intellectual disabilities. Participants in the included articles were recruited from local community-based service agencies (*n* = 2) or at sites with existing sexual education programs (*n* = 1), and records of participants taking part in a sexual education program (*n* = 1). All included articles used participant self-report to measure outcome data.

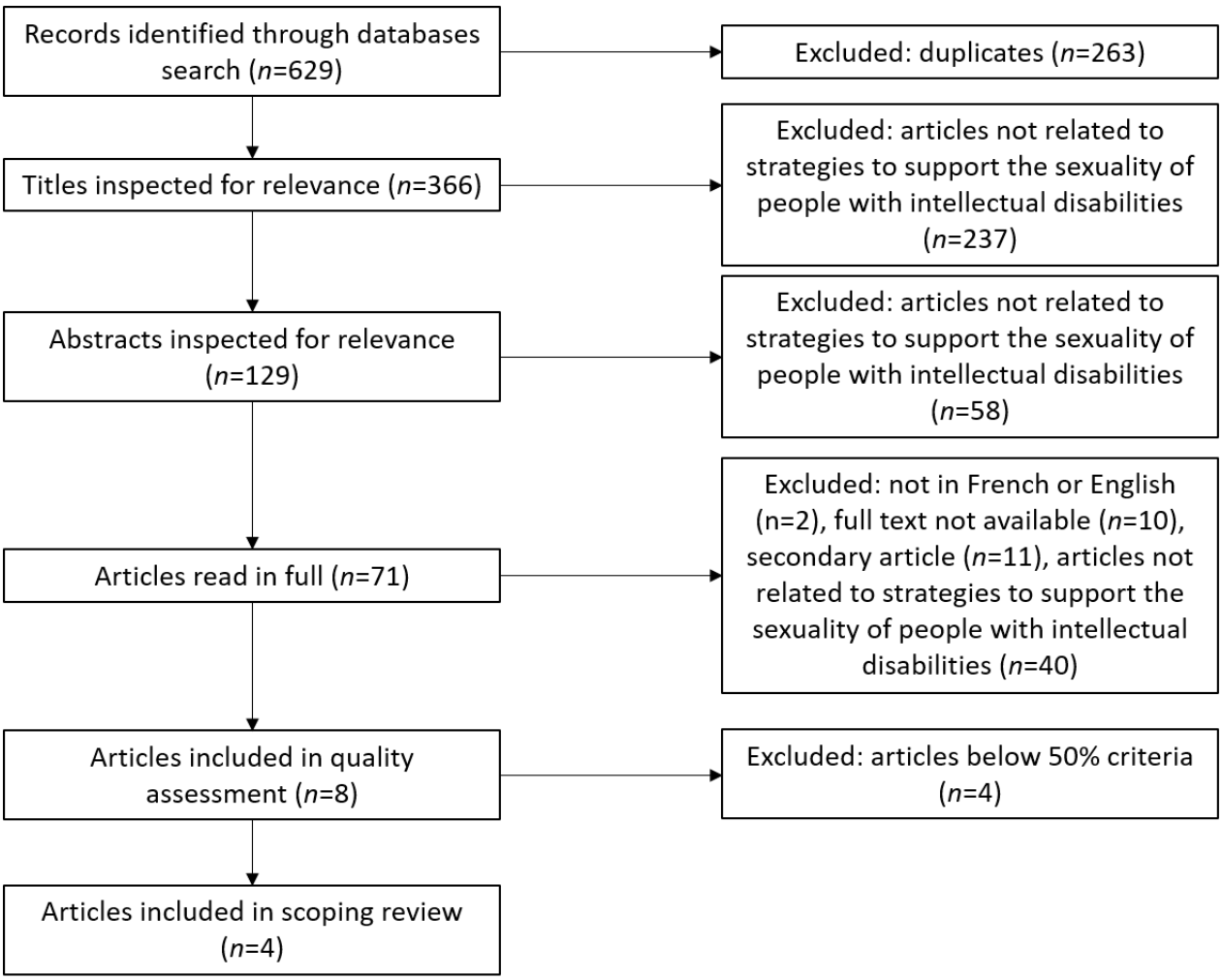


Figure 3.1 Flowchart showing selection process for scoping review

Table 3.2 *Summary of research on strategies for supporting the sexuality of persons with ID*

Author (Year), Location	Sample selection	Methods	Key findings
Caspar, L. A. & Glidden, L. M. (2001), United States Strategy: Caspar and Glidden's sexual education program	Receiving residential services from a community-based residential and vocational services provider • *n = 12*, adults with intellectual disabilities (9 women, 3 men), aged from 28-62 years (Mean = 38.7)	Pre-test/post-test study Constructed two sexual awareness, knowledge and attitudes forms (A and B) administered to two groups	• Significant difference between participant pre-test and post-test scores for sexual factual knowledge (F [1,10] = 20.80, p = 0.001) • For 50% of participants, significant differences in subjective perception of control over their own sexuality, and their values and opinions in a positive direction (t [11] = 3.02, $p < 0.05$) • Anecdotal evidence that program increased awareness of sexuality issues among participants and opportunities for learning
Friedman, C., Arnold, C. K., Owen, A. L., & Sandman, L. (2014), United States Strategy: Nominal Group technique (NGT)	Identifying as self-advocates through self-advocacy groups, word of mouth, and disability advocacy and service agencies • *n* = 35, adults with intellectual disabilities (men and women), 50% people of color	Exploratory, during community research forum Group discussion, small group role-plays, the nominal group technique and circle closure discussion Member checking post-analysis with 2 members who attended the forum	• Themes: speaking up for yourself, speaking up for others, getting information, being confident in myself, my choices, rights, respect for others, and speaking out against abuse • Facilitators to sexual self-advocacy: expanding access to information and sexual health services, removing systemic barriers, educating others, increasing access to counseling, and developing opportunities for sexual expression
Author (Year), Location	Sample selection	Methods	Key findings

Garwood, M. & McCabe, M. P. (2000), Australia Strategies: Co-Care and Family Planning Victoria (FPV)	From records of participants who would be taking part in each sex education program • *n* = 6, men with intellectual disabilities (3 in Co-Care program, 3 in Family Planning Victoria (FPV) program), aged from 12-15 years (Co-Care) (Mean = 19, SD = 6.5) and 28-32 (FPV) (Mean = 31.6, SD = 3.2)	Pre-test/post-test study using Sexuality Knowledge, Feelings and Needs Scale for People with Intellectual Disabilities (Sex Ken-ID) Two sexual education programs: Co-Care (10 weekly sessions, 2h each) and FPV (6 weekly sessions, 1h each)	• Minimal increase in sexual knowledge at the end of the program Sexual knowledge: • Co-Care: increase for friendship, marriage, sex, contraception, pregnancy and homosexuality. Slight increase in body part identification, sexual interaction and STDs • FPV: increase in the domains of sex, contraception, pregnancy and STDs • Low knowledge about masturbation and menstruation remained Feelings: • Increase in both groups in positive feelings towards female friendships and hugging someone of the opposite sex • Negative feelings towards girlfriends, masturbation, oral-genital sex, and sexual intercourse remained • Increase in negative feelings towards marriage, having children and being present during childbirth

Author (Year), Location	Sample selection	Methods	Key findings

Frawley, P. & Bigby, C. (2014), Australia Strategy: Living Safer Sexual Lives: Respectful relationships (LSSL:RR)	From 3 program sites in Victoria and one in Tasmania • *n* = 16, adults with intellectual disabilities (13 women, 3 men), aged from 20-40 years, trained as peer educators	2 semi-structured in-depth interviews, direct observations Interviews: 1 after completion of training and 1 after delivering or participating in the LSSL: RR program Unstructured observations and field notes Thematic analysis	• Themes: helping others, being seen as and feeling like credible sources of knowledge and experiences, being role models for people who attended the education program and for persons with an intellectual disability more broadly, and developing their own knowledge and skills • Peer education is both perceived and experienced as a beneficial approach

Quality Assessment Results

Studies included in the scoping review were of moderate to high methodological quality (see Table 3.3); however, some limitations were noted. First, three studies have gender biases: Garwood & McCabe (2000) included only men with intellectual disabilities; in contrast, men were not equally represented in Caspar & Glidden (2001) and Frawley & Bigby (2014). All outcome data were measured through participant reports; thus, social desirability and recall bias may have been present. Regarding the analysis, none of the studies included a control group. Additionally, all four studies had small sample sizes; for this reason, findings are not generalizable and may be limited in their ability to detect meaningful differences between pre- and post-test.

Table 3.3 *Quality assessment results*

Methodological quality criteria	Article reference			
	Caspar et al., 2001	Frawley & Bigby, 2014	Friedman et al., 2014	Garwood & McCabe, 2000
Screening S1. Clear research questions (or objectives)?	X	X	X	X
S2. Collected data address the research question (objective)?	X	X	X	X
Qualitative 1.1. Are the sources of qualitative data relevant?		X	X	
1.2. Is the process for analyzing qualitative data relevant?		X	X	
1.3. Is appropriate consideration given to the data collection context?			X	
1.4. Is appropriate consideration given to how findings relate to researchers?			X	
Quantitative descriptive 4.1. Is the sampling strategy relevant to address the research question?	X		X	X
4.2. Is the sample representative of the population understudy?				
4.3. Are measurements appropriate?				X
4.4. Is there an acceptable response rate (60% or above)?	X		X	X
Mixed methods 5.1. Are the mixed methods research design relevant?				
Methodological quality criteria	Article reference			

	Caspar et al., 2001	Frawley & Bigby, 2014	Friedman et al., 2014	Garwood & McCabe, 2000
5.2. Is the integration of qualitative and quantitative data (or results*) relevant?			X	X
5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?			X	X
Score (%)	50	50	75	75

Note: For full description of MMAT items refer to Pluye et al. (2011).

Description of the Strategies

Among the four included articles, the authors identified five strategies. Four of these strategies were sexual education programs: Caspar and Glidden (2001), Co-Care, Family Planning Victoria, and the Living Safer Sexual Lives: Respectful Relationships. The other strategy consisted of using the Nominal Group Technique to discuss sexuality with adults with ID.

Caspar and Glidden's (2001) Sexual Education Program. This study presents a sexual education program aiming to increase the sexual knowledge of adults with ID in residential services. This six-session program, lasting 2h30 to 3h each, includes a curriculum, diagrams, documents, videos, and tests for participants. The documentation includes information on sexually transmitted infections and contraceptives, including a document by Planned Parenthood on different contraceptive methods. This program used physical models of condoms and models of reproductive organs and diagrams representing both men and women's sexual and reproductive anatomy and the menstrual cycle. Furthermore, Circle Concept helped participants identify the persons surrounding them according to the level of familiarity. A pre and post-test method determined if participation in the program increased sexual knowledge and changed negative attitudes towards sexuality for persons with ID. Study findings show that sexual factual knowledge increased significantly after participation in the program ($F(1,10) = 20.80$, $p = 0.001$). For 50% of the participants, perception of control over their sexuality and their values and opinions in a positive direction significantly increased ($t(11) = 3.02$, $p < 0.05$). Participants reported an increase in awareness of sexuality issues among participants and opportunities for learning following the program.

Furthermore, Caspar and Glidden (2001) report that the program is short yet intensive, inexpensive, publicly available, or easily recreated. Finally, results were obtained in a service agency context, which suggests transferability to similar community-based services. There are several limitations to this program. First, included participants were primarily persons with ID who had previously exhibited sexually inappropriate behaviours (8 out of 12). For this reason, findings may not be generalizable to all persons with ID. Second, the role of the instructor was not clearly defined. The instructor facilitated the program delivery, managed crisis and distractions, and facilitated psychiatric, psychotherapeutic, and behavioural services. The authors suggested adding an assistant, such as agency support staff, to the program delivery team for this additional support role. Finally, it would be beneficial to have more program sessions with fewer participants per session.

Co-Care. One of the two programs presented in Garwood and McCabe's study (2000), Co-Care is a sexual education program to increase sexual knowledge and positive feelings towards sexuality. This program included the following topics: emotions, body language, social skills, human life cycle, puberty, body awareness, private and public behaviours, sexual relations, conception, pregnancy and giving birth, contraception and sexually transmitted infections, menstruation, and protective behaviours. The program was administered in 10-weekly sessions, lasting 2 hours per session and using two instructors (one man and one woman). Like the previous program, a pre and post-test method were used to determine if participation in the program increased sexual knowledge for persons with ID; however, this study used the same assessment tool, the Sex Ken-ID, at pre- and post-test to measure changes in knowledge. The Sex Ken-ID is a 248-item interview designed to assess the sexual knowledge, experience and needs of persons with ID. A previous study evaluating the psychometric properties of this scale

revealed moderate to a high level of internal consistency across knowledge, needs, and feelings area (e.g., Sexual interaction .57 − .86 and Dating and intimacy .47 − .79) and moderate to high test-retest reliability (e.g., Sexual interaction .52 − .84 and Dating and intimacy .60 − .79) (McCabe, Cummins, & Deeks, 1999). At post-test, only minimal increases in sexual knowledge were found. Knowledge increased in friendship, marriage, sex, contraception, pregnancy and homosexuality, and a slight increase was found for body part identification, sexual interaction, and sexually transmitted infections. Slight increases in positive feelings were found towards female friendships and hugging someone of the opposite sex, while negative feelings towards girlfriends, masturbation, oral-genital sex, and sexual intercourse remained after the program delivery. However, it was impossible to analyze quantitatively pre- and post- test scores from the Sex Ken-ID because of the small sample size.

Family Planning Victoria. The second program presented in Garwood and McCabe's study (2000), Family Planning Victoria (FPV), also aimed to increase sexual knowledge and positive feelings towards sexuality. Topics covered by this program were slightly different than in the Co-Care program. These were: emotions, body awareness, private and public body parts and behaviours, sexual relationships, contraception, AIDS, protective behaviours, self-awareness, and friendship and relationships. FPV is a 6-week sexual education program lasting one hour each with one instructor. The authors used the Sex Ken-ID to measure changes in sexual knowledge and positive feelings towards sexuality at pre- and post-test. Study findings showed minimal increases in sexual knowledge. These were in the areas of sex, contraception, pregnancy, and sexually transmitted infections. Like the Co-Care program, participants had increased positive feelings towards female friendships and hugging someone of the opposite sex, while negative feelings remained towards girlfriends, masturbation, oral-genital sex, and sexual

intercourse. This program also had limitations in generalizing findings due to the small sample size.

Living Safer Sexual Lives: Respectful Relationships. Developed from an older program, Living Safer Sexual Lives, the LSSL: RR, presented in Frawley and Bigby (2014) includes a program co-facilitator with an ID. This program was informed by 25 real-life stories of adults with ID obtained from multiple consultations. It consists of 4 sessions on different topics: (1) Discussing sexuality and sexual relationships, (2) Having rights and being safe, (3) Respectful relationships, and (4) Men and respectful relationships. Participants in this program were encouraged to involve a community member as a learning partner who will support the adult with ID throughout the program. The program also engaged the community by training staff from community-service agencies supporting individuals with ID as program co-facilitators.

Furthermore, it relied on a partnership between adults with ID, agency staff and community members, reinforcing the link between professionals working in the community and services available. Study findings showed that being a peer educator with an ID in the LSSL: RR program gave a sense of empowerment, positioned them as credible sources of information about relationships, enabled them to help others, and allowed them to learn new knowledge about respectful relationships, community resources and supports, and new skills. In this study, peer education was both perceived and experienced as a beneficial approach to sexual education. There were fundamental limitations in this study. First, the study had a small sample (n=16); thus, findings may not be generalizable to all persons with ID receiving supports in a community-based service agency. Second, gatekeeping was prominent in this study; some service agency personnel did not support the peer-education model. There were beliefs that

adults with ID do not have the capacity to be facilitators or cannot speak of respectful relationships if they do not have these types of relationships in their lives.

Nominal Group Technique. The Nominal Group Technique (NGT) in Friedman and al. (2014) was used to structure discussions on how adults with ID define and experience sexuality as sexual self-advocates. The NGT includes non-judgmental, structured, and easy-to-understand discussions for persons with ID facilitated by a person without an ID. The NGT also provides space for adults with ID to share their opinions and experiences. Furthermore, activities, such as role-play on relationships and security, were used to familiarize participants with NGT questions. Steps of the NGT included: (A) Asking a question to participants and allowing time to reflect, (B) Asking participants to write their answers down on a piece of paper, (C) Share their ideas with the group, one at a time and one idea at a time, (D) Writing down ideas on a board and combining similar ideas into themes, (E) Discussing themes with the group, restructure and validate themes, and (F) Voting on the themes to prioritize them. Themes emerging from the NGT on sexual self-advocacy included: speaking up for yourself, speaking up for others, getting information, being confident in myself, my choices, rights, respect for others, and speaking out against abuse. This study also identified facilitators to sexual self-advocacy such as expanding access to information and sexual health services, removing systemic barriers, educating others, increasing access to counselling, and developing opportunities for sexual expression. The NGT is a short and inexpensive strategy that may be used by agency personnel to incorporate ideas from persons with ID on topics such as security, private-life, and sexual relationships. However, one significant limitation was that the group in this study was too large (n= 35) to facilitate a discussion with adults with ID. Furthermore, this strategy may be too challenging for adults with ID with greater support needs or significant communication limitations.

Discussion

In this review, very few articles met the inclusion criteria. From these four articles, five different strategies to support the sexuality of persons with ID were identified and included four different sexual education programs and a method for accessible group discussions on sensitive topics such as sexuality. The sexual education program by Caspar and Glidden (2001) increased factual knowledge significantly after participation in the program. For half of the participants, their perception of control over their sexuality increased as well. In the two sexual education programs in Garwood and McCabe (2000), Co-Care and Family Planning Victoria, knowledge and positive feelings following both programs' implementation increased minimally. However, negative feelings remained for attendees of both programs towards girlfriends, masturbation, oral-genital sex, sexual intercourse, and an increase of negative feelings towards marriage, having children and being present during childbirth. In the sexual education program by Frawley and Bigby (2014), Living Safer Sexual Lives: Respectful Relationships, peer educators reported many benefits of participating in the program, such as increased empowerment, being a credible source of information, helping others, and increased opportunities to learn skills, knowledge on respectful relationships, and of existing community resources and supports. Finally, the last strategy included was the Nominal Group Technique used by Friedman and al. (2014). Participants identified themes around sexual self-advocacy, such as speaking up for yourself and others, getting informed, being confident, having choices, knowing your rights, respecting others, and speaking out against abuse.

From these findings, there is evidence that the content of the included sexual education programs has been updated compared to previous studies. Previous reviews suggest that sexual education programs focused primarily on the prevention of negative aspects of sexuality such as

unwanted pregnancies, sexually transmitted infections, and sexual abuse (Conod & Servais, 2008; Schaafsma et al., 2013) and lacked information on emotional and psychological sexual experiences (Thompson, 2001), intimacy and pleasure (Gordon & Ellingson, 2006). All sexual education programs identified in this review included topics beyond preventing risks, such as masturbation, same-sex relationships, marriage, and communication about intimate relationships (Caspar & Glidden, 2001; Frawley & Bigby, 2014; Garwood & McCabe, 2000). However, available information about included strategies and their curricula was limited. The primary researcher directly contacted authors when study material was unavailable. Respondents provided little documentation, or documentation was simply nonexistent or in a format not compatible with commonly used software.

For this reason, it was not possible to determine the extent to which each topic was covered. Furthermore, the identified strategies are moving away from traditional strategies aimed solely at increasing sexual factual knowledge to support the sexuality of persons with ID. For example, one sexual education program also aimed to increase positive attitudes towards sexuality (Caspar & Glidden, 2001), two others aimed to increase positive feelings (Garwood & McCabe, 2000), and one program explored the experiences of those involved in the program delivery (Frawley & Bigby, 2014). However, it is unclear whether the acquired knowledge and increased positive feelings and attitudes can be generalized and transferred into daily life skills and behaviours (Blanchett & Wolfe, 2002; Schaafsma et al., 2015).

Different formats were identified in the included strategies to deliver the sexual education programs. These programs used pictorial support, videos, role-play, and realistic physical models of sexual organs and contraceptive methods (Caspar & Glidden, 2001; Frawley & Bigby, 2014). Previous research has shown that role-play scenarios, which require a certain degree of

abstraction, may be too complex for persons with ID with more significant support needs (Grieve et al., 2007). Finally, it is difficult to establish whether pictorial supports aid or hinder recall and participant recognition during participation in sexual education programs (Grieve et al., 2007). A novel approach to providing sexual education for persons with ID used by Frawley and Bigby (2014) was peer education (Anderson, 2015; Wacker et al., 2009). Peer education successfully engages youth without ID to address sexual and reproductive health needs (Price & Knibbs, 2009).

Furthermore, sexual education taught by peers may use methods that are more appropriate, accessible, and interesting for those participating (Forrest et al., 2002). This is especially important for persons with ID as sexual education programs or social skills training may be overly complicated for individuals with higher levels of support (Grieve et al., 2007). However, little is known about the effectiveness of peer education with persons with ID (Black & Roberts, 2009) other than the benefits reported by peer educators with ID (Frawley & Bigby, 2014). Another novel approach identified in this review to support the sexuality of persons with ID was the use of the Nominal Group Technique (NGT) in Friedman et al. (2014). This structured group discussion method has been used in previous studies to address challenging and taboo subjects for persons with ID (Owen et al., 2016). This inclusive method provides time and space for persons with ID to share their ideas on a given topic and choose which ideas have more importance. This process may empower persons with ID who may have been excluded from research (Tuffrey-Wijne et al., 2007). Unfortunately, the NGT is not a method well suited to persons with ID with high support needs, as it requires writing, verbally sharing ideas, and reading responses. In Tuffrey-Wijne et al. (2007), authors suggest using images and visual reminders of the ideas to facilitate the sorting and ranking to assist those with high support

needs. With the small changes suggested by Tuffrey-Wijne et al. (2007), the NGT may become an accessible method. These approaches, which differ from traditional sexual education programs to support the sexuality of persons with ID, are interesting; however, there is a need for evaluation to understand which methods of providing sex education are the most effective (Schaafsma et al., 2013).

There are persistent problems around the quality of research evidence to support the sexuality of adults with ID. First, many strategies to support individuals with ID have little evidence of their efficacy or effectiveness (Goin-Kochel et al., 2009) or have been demonstrated to be ineffective (Goin-Kochel et al., 2009). In this review, all included strategies lacked long-term follow-up measures. Second, there is a paucity of information provided by authors on the strategy evaluated in their study (Schaafsma et al., 2015). There was a lack of information in the included articles on how and why the sexual education programs were developed and insufficient details on program materials and curricula. Third, previous research has shown that sex education programs tend to be practice rather than theory- or evidence-based (Schaafsma et al., 2013). In Garwood and McCabe (2000) and Caspar and Glidden's (2001) study, there is no reference to theory or evidence to develop the included sexual education programs. It is difficult to establish whether there was a lack of use or if evidence simply did not exist when these older programs were developed. However, the ecological abuse prevention model presented in the sexual education program by Frawley and Bigby (2014) is based on previous research (Fitzsimons, 2009; Hollomotz, 2009; Sobsey, 1994) and existing health, violence, and abuse prevention models (Victorian Health Promotion Foundation, 2007). Finally, similarly to previous research in ID (Sturmey, 2014), most evidence in this review comes from experiments with small samples and no control group. For these reasons, it is difficult to determine in which contexts

these review findings apply. Future research should consider building on the existing evidence to identify best and promising practices to support the sexuality of persons with ID.

Limitations

There are a few notable limitations. First, very few studies were included in the review. We may not have identified all relevant studies in PsycINFO, ProQuest and Academic Search Complete, given the use of broad terms to identify strategies beyond sex education and restrictions to quality assessment. Studies evaluating other sexual education programs may not have been identified in this review. For example, Dukes and McGuire (2009) and Hayashi et al. (2011) were not included in this review. Upon further consultations with a university librarian, these were not included due to searches using keywords rather than titles and abstracts to identify relevant articles. However, searches through keywords yielded more results relevant to the search objectives than searches through titles and abstracts, which yielded articles related to broader aspects of sexuality. There is a need for coherence in search strategies in future studies to increase identification in databases. Second, no French studies were included in the review. It is possible that French researchers are choosing to publish in English to reach a larger audience. Additionally, most French articles are from France, typically accessed using the CAIRN database. Databases used for this search using English keywords may not capture articles published in French using French keywords.

Conclusion

Persons with ID face many barriers towards their sexuality, including lack of information and opportunities to explore their sexuality. Most sexual education programs identified in this review showed minimal increases in sexual knowledge and thus may not suffice to support the sexuality of persons with ID. For this reason, it may be essential to explore other types of support

strategies. For example, personnel from service agencies providing services to persons with ID could be involved in sexuality education. Persons with ID may rely on agency personnel to answer their questions and provide guidance. Service providers may not feel like they have sufficient training to support the sexuality of persons with ID; however, they directly influence how persons with ID view and experience their sexuality. To facilitate the transfer of knowledge on the strategies with the highest level of evidence, strategies identified in this review were made available in the form of a working document. This effort aimed to make research evidence more accessible to relevant stakeholders. This will be discussed in detail in the following section.

Section 2. Engaging Various Stakeholders to Implement Change

In this section, we cover steps 2 to 6 of the Implementation of Change Model. We shifted the focus from knowledge identification to contextualization and feasibility of implementing the strategies within the service agency.

Section 2 is split into four subsections. First, we describe a series of focus groups with various stakeholders to contextualize the scoping review findings. Second, we describe how knowledge was consolidated and made available to various stakeholders. In this subsection, we also explored interactions and decision-making among various stakeholders on a common issue. The following subsection provides information on the development and implementation of the chosen strategy within the service agency. The fourth and final subsection is the discussion of Section 2.

1. Contextualizing Knowledge to the Target Setting

In the second step of the Grol & Wensing Implementation of change model (2013), current practices are reviewed and assessed to determine the most significant deviations from what research and stakeholders considered best practices.

In this study, we assessed existing services provided to support the sexuality of persons with ID and whether this matched any of the identified strategies in the scoping review. From this analysis, the primary researcher gained insight into what elements of the strategies were already implemented. Furthermore, consultations in this step allowed us to identify the experiences and preferences of various stakeholders and potential implementation considerations for each strategy identified through the scoping review.

Introduction

Interventions are more readily adopted if tailored to the individuals' specific needs and context (Hale et al., 2011; Storey, 2007). To effectively tailor these interventions, insight is needed into the target group's characteristics and the potential facilitators and barriers of the setting (Bartholomew et al., 2011; Grol & Wensing, 2013; Kuijken et al., 2016). For interventions supporting persons with ID, research suggests involving caregivers and support staff when tailoring interventions (Hale et al., 2011; Young et al., 2012). Understanding all stakeholders' potentially varying goals and interests before planning the implementation of an intervention is an essential step of the context analysis (Grol et al., 2013). Finally, sharing knowledge on deviations from evidence-based and informed practices may act as a motivator of change for stakeholders (Grol & Wensing, 2013) who may overestimate the quality of their support (Davis et al., 2006).

For this study step, the primary researcher chose to conduct focus groups to gather relevant information on the settings' current supports for the sexuality of persons with ID. Researchers often use focus groups with persons with ID (McCallion & McCarron, 2004; Nind, M, 2008). First, focus groups create a safe environment for discussion through building confidence, peer support and validation (Cambridge & McCarthy, 2001). Furthermore, focus groups in non-medical settings such as service agencies encourage participants with disabilities to be open and honest, consequently having a more active role in the study (Llwellyn P, 2009). Second, they enable the participation of persons with ID with higher support needs who are often excluded from research (Feldman et al., 2014; Gibbs et al., 2008). Previous research has shown that focus groups successfully access the views of persons with ID (Gibbs et al., 2008). Finally, the accuracy of information shared by participants with ID increases with existing trust and

rapport (Tassé et al., 2005). Another study involving persons with ID in diabetes screening research revealed that established group dynamics encouraged participants to speak and build on each other's experiences (Tyrer et al., 2017). Creating a safe and familiar environment was important as participants had no previous contact with the primary researcher.

Using focus groups, we aimed to understand if the strategies identified in the scoping review applied to the service agency and how they could be tailored to fit the needs of various stakeholders. Specifically, we aimed to 1) understand the participants' perspectives about the existing supports provided by the service agency, 2) obtain the input of stakeholders on the strategies identified in the scoping review, and 3) discuss potential implementation considerations.

Method

Setting. Two separate groups were created for the focus groups to mirror the existing division on the types of supports provided to persons with ID. The first group (Group A) was for front-line staff providing residential services and for persons with ID and caregivers using this service. The advisory committee members described persons with ID in this group as having high support needs, basic sexual knowledge, and an individual sexuality (i.e., non-relational). The second group (Group B) was for front-line staff from adult support services, including but not limited to providing support with budgeting, buying groceries, medical appointments, ensuring a balanced diet, and being present for health and security. Caregivers in this group may also receive respite services. Persons with ID in this second group were identified as having limited support needs, being knowledgeable about sexuality, and having a relational sexuality (i.e., various degrees of partnerships or engaging in diverse sexual practices).

Recruitment of Participants. Stakeholders participating in the focus groups included persons with ID (i.e., persons with ID currently receiving services from the service agency), front-line staff and family caregivers. Participants were included if they: 1) were over 18 years of age, 2) currently provided or received services from the target agency, and 3) had sufficient communication and comprehension skills to provide consent and partake in the focus groups.

Committee members distributed invitation letters and consent forms to potential participants, including the study's purpose and provided researcher contact information. Documentation for persons with ID was modified to meet accessibility guidelines for persons with ID (United Kingdom Government, 2016). This included shorter sentences and larger font. The larger font was also used for the direct phone line to call for further information. We wanted to ensure that participants understood the aim of the study, their role and understood their rights as participants (e.g., to withdraw from the study at any time) (Cameron & Murphy, 2007).

Participants. See Table 3.4 for the number of participants for each focus group. We present additional information about each participating stakeholder below.

Table 3.4 *Sample size for each focus group discussion with group A and B*

Focus Groups	Session	Number of Participants		
		Persons with ID	Staff	Caregivers
Group A	1	7	8	6
	2	6	-	-
	3	7	-	-
Group B	1	5	12	2
	2	4	-	-
	3	4	-	-

Persons with ID. A total of 8 persons with ID participated in focus group A. One person with ID no longer wished to participate after the first session, and one new person with ID was added at the last session. A total of 8 persons with ID participated in focus group B. Two persons with ID were absent in the second session, and one new person with ID was added in the second session. In the third session, two participants from the previous session did not attend, and two new participants were added.

Front-line staff. A total of 8 front-line staff participated in focus group A, whereas a total of 12 front-line staff participated in focus group B.

Caregivers. Caregiver participation was limited. A total of 6 caregivers participated in group A, and only two caregivers from the same family participated in group B.

Procedure. Each stakeholder (i.e., persons with ID, front-line staff, and caregivers) participated in separate focus groups per group (Group A and B) for a total of 10 focus groups

(see Table 3.4). The primary researcher facilitated focus groups. An undergraduate student (DL) observed all discussions but did not participate.

Before every focus group, the primary researcher described the study and informed participants that discussions were audio-recorded and explained the anonymity and confidentiality of the information shared. Furthermore, the primary researcher answered questions and obtained informed written consent. Participants were informed that all discussions were audio-recorded. Participants were given refreshments.

Focus groups began with an introduction of all participants and a presentation of the focus group rules. The facilitator continued with an ice-breaking activity by asking participants to share words to describe sexuality. A semi-structured discussion followed on topics identified by the primary researcher to gain insight on current practices and potential implementation considerations for the strategies identified in the scoping review. The discussion topics included 1) quality of existing supports, 2) strategies identified in the scoping review, and 3) implementation considerations. There are additional details about the discussion topics in Appendices A for focus groups with front-line staff and caregivers, and B1 to B3 for focus groups with persons with ID. Front-line staff and caregivers participated in one focus group, lasting one hour, for each group (A and B). Focus groups for persons with ID were adapted to be more accessible. Persons with ID participated in a series of three focus groups per group. Each focus group focused on one of the three topics mentioned previously. These focus groups were slightly shorter than focus groups for front-line staff and caregivers, lasting 45 minutes each. Participant responses were also written on a flipchart and used to summarize critical information.

Data Collection and Analysis. The primary researcher took notes during all focus groups. The primary researcher also used member checking in real-time throughout all discussions to ensure the reliability of the information collected (Kidd & Parshall, 2000). Finally, the primary researcher provided a summary at the end of each focus group to ensure that they captured the main messages. An undergraduate student observer (DL) documented participant reactions and interactions and extracted key messages for summaries at the end of each focus group. These notes were added to group recordings for the analysis described below.

All focus group recordings were transcribed verbatim. We conducted a pre-structured case summary analysis using QSR's NVivo 12 (QSR International Pty Ltd, 2019) (see Appendix C). The primary researcher drafted an outline before data collection consisting of headings that directed the analysis to answer specific objectives for this part of the study (Miles, 1990). This method combines data collection, analysis, and reporting into one step and simplifies cross-case analysis. The primary researcher completed an outline for each case in this study, associated with a stakeholder group: persons with ID, caregivers, and front-line staff. Outlines were audited by a senior researcher[5].

Findings

We present findings according to the three major themes from the pre-structured summary outlines. First, we present how each stakeholder perceived the quality of the support provided by the service agency to support the sexuality of persons with ID. This includes mentions of potential challenges and improvements to be made to current supports. Second, we present which strategies were preferred by each stakeholder and potential implementation

[5] Senior researcher refers to the supervisor of NP, Dr. Virginie Cobigo.

considerations. For each subsection, findings are divided per stakeholder: persons with ID, front-line staff, and caregivers.

Quality of Existing Supports. Each stakeholder provided a different perspective of the services provided by the service agency. Persons with ID shared their lived experiences as persons with ID, front-line staff provided the perspective of service providers, and caregivers validated information from an external perspective on the support provided by the service agency and the impact in the community.

Persons with ID. Persons with ID recognize the vital role the service agency plays in their daily lives. For example, the service agency organizes multiple activities for persons with ID to meet new people. These include bowling events, dances, movie nights at the theatre, holiday parties, barbecues, and outings to the pool. Persons with ID report having open communication with agency personnel. When persons with ID need support or have questions about sexuality, they ask the front-line staff assigned to them for advice: *« Si je poses des questions, elle me donne un (conseil) »*. Persons with ID also reported having never received any sexual education at the service agency. Most participants reportedly received sexual education from their families or in school.

In terms of improvements to existing supports, persons with ID mentioned receiving some negative comments while at the service agency: *« On peut changer ça facilement parce qu`il y a des personnes qui disent de mauvaises choses à la personne »*. Another person with ID reported feeling embarrassed with their partner because of what front-line staff might say: *« Tu penses à ce que les travailleurs vont dire à propos de toi. Comme si je vais apporter mon chum, puis tu dis qu'il a une déficience, c'est un petit peu gênant »*. Finally, persons with ID noted

limitations to the support provided by front-line staff in their daily lives. For example, one person with ID reported not being accompanied by their front-line staff when in court for a child custody hearing: *« Je trouve ça injuste. Il devrait au moins avoir quelqu'un qui devrait être un peu plus amical. J'ai essayé de faire une travailleuse sociale s'asseoir avec moi mais elle ne pouvait même pas être là toute la journée »*.

Front-line Staff. Front-line staff report supporting persons with ID with the same activities mentioned by the latter. Some activities were strictly organized by the service agency, others by the *Mouvement des personnes d'abord* (People First Mouvement), an advocacy group led by persons with ID. Although this group is independent of the service agency, many persons with ID receive support from the agency's front-line staff. Focus groups with front-line staff also revealed that the service agency does provide support towards the sexuality of persons with ID. For example, the service agency purchased one sexual education program, the *sexo-trousse* (Lemay & Belley, 1996); however, this program is dated and rarely used by front-line staff. Another front-line staff recalled using the Circles program (Walker-Hirsch & Champagne, 1991) to support persons with ID in identifying social boundaries in relationships. They also report consulting external services, such as the Catholic Family Service Ottawa, when the necessary support extends beyond their knowledge and competencies. In terms of training, front-line staff report never having received any form of training on supporting the sexuality of persons with ID. The only related training was given in the same year as the study by the *Centre d'aide et de lutte contre les agressions à caractère sexuel* (CALACS), an organization supporting survivors of sexual abuse. In terms of service agency policies and procedures, there are no existing policies towards sexuality, other than a policy on abuse. Another generic policy that could apply to

sexuality was that persons with ID could not be permitted to do something illegal, such as masturbating in public, even if they chose to do so:

> *« On a une politique écrite quelque part qu'on ne peut pas laisser la personne faire quelque chose d'illégale. Se masturber en public, ce n'est pas légal. On ne peut pas laisser la personne faire quelque chose d'illégal parce que c'est son choix non plus. »*

Front-line staff reported challenges in supporting the sexuality of persons with ID. As there is no formal training on this topic, front-line staff rely on their knowledge, culture, and values to support the sexuality of persons with ID. One front-line staff reported that the sexuality of persons with ID is expressed differently based on the individual currently offering support. It is important to remind themselves to put one's beliefs and values aside to prioritize the needs of persons with ID:

> *« J'ai déjà vu certaines conseillères ou conseillers utiliser leurs valeurs personnelles. (Il faut) toujours se faire un rappel que tu sais que tu peux avoir certaines croyances, certaines valeurs, mais il faut que je mette ça de côté et que je regarde la personne. »*

For example, acceptable sexual behaviours vary. Some front-line staff imposed their values onto persons with ID by telling them that they cannot engage in sexual relationships outside of marriage:

> *« Mais, il y a certaines personnes qui vont penser que pour avoir une relation sexuelle, ils doivent être mariés. (…) Mais là, (personnel de soutien) va voir sa personne en train d'avoir une relation avec telle personne. Elle va dire 'non, tu n'as pas le droit'. C'est mettre ses valeurs, mais c'est ça des fois. »*

Although there seems to be incoherence in how support is provided by front-line staff, front-line staff agreed that no support was given unless prompted by persons with ID or presented with sexually inappropriate behaviours.

Caregivers. Caregivers reported positive feedback on the support provided by the service agency, such as compassionate care, warmth, and motivation to help: *« Il y a beaucoup d'humanité et de chaleur dans cette organisation »*. When caregivers require support, the service agency finds a solution to answer their needs; however, supporting resources and services were only provided following their request. In addition to activities mentioned by persons with ID, caregivers also highlight workshops given by the *Mouvement des personnes d'abord* (People First Mouvement). They also report having no formal sexual education program within the agency but expressed past experiences with the Circles program (Walker-Hirsch & Champagne, 1991). Caregivers mentioned that front-line staff provided support when required. Much like front-line staff, caregivers report no existing policies, procedures, or consensus on how to support the sexuality of persons with ID. Support relies on front-line staffs' attitudes, beliefs, and values: *« Là encore, les gens ne sont pas tous d'accord sur un comportement qui est correct ou qui n'est pas correct »*. Finally, caregivers report that front-line staff directly influence whether persons with ID will discuss sexuality openly. The openness of persons with ID to talk about sexuality may depend on how front-line staff react: *« À moins qu'il y ait une réaction de la part du personnel (…) Ça peut être important aussi pour voir s'il va se fermer ou s'il va s'ouvrir »*.

Implementation Considerations. The two preferred strategies by all stakeholders were the Nominal Group Technique (NGT) by Friedman and al. (2014) and the Living Safer Sexual Lives: Respectful Relationships (LSSL:RR) program by Frawley and Bigby 2014. Stakeholders

also shared potential implementation considerations specific to these strategies and for any new intervention within the service agency.

Persons with ID. Persons with ID found many benefits of the peer education component in the LSSL:RR program. One person with ID mentioned that peer education shows persons with ID that they are not alone in experiencing trauma and may gain hope and confidence in overcoming challenges.

> *« Je pense que ça montre qu'ils ne sont pas tous seuls– Quand tu as une déficience intellectuelle, tu vis des traumatismes, tu vis des choses que d'autres personnes ne vivent pas. Au moins, la personne, ils vont voir que, comme elle a une déficience intellectuelle, moi je peux aussi changer des choses dans moi. Ça donne un peu de confidence et d'espoir aussi parce que, des fois, tu ne penses pas surmonter des choses, mais tu surmontes. »*

Persons with ID perceived many benefits to peer education, such as increased familiarity and credibility of having peers as instructors. Many expressed a desire to become an instructor of the program if implemented in the service agency.

The second strategy favoured by persons with ID was the NGT. They found this strategy useful; however, they would like topics and group members to vary at each session. For example, one person with ID suggested using the NGT with an all-female group. Another person with ID mentioned that they could not read, highlighting the need to modify the NGT by Friedman and al. (2014) to include those with varying literacy skills.

In terms of implementing change within the service agency, persons with ID would like workshops or sexual education programs to learn about sexuality. They mentioned the need to

modify the content according to the participants. For example, some persons with ID preferred learning about differences between the sexes and genders, puberty, pregnancy, sexual relationships, and diverse sexual practices. Others mentioned wanting more in-depth sexual education by discussing topics such as emotions and taking care of children. As for how sexual education should be delivered, persons with ID were also divided. Some preferred one-on-one sessions, as they are more private and less embarrassing, whereas others preferred having a group discussion to share similar experiences. One person with ID reported that group discussions are helpful as others may have experienced similar problems:

> *« Moi, ça serait en groupe parce que des fois ça peut aider la personne. (Il y a) d'autres personnes qui peuvent avoir des problèmes similaires, semblables à ton problème. Savoir qu'il y a en d'autres, que tu n'es pas la seule personne qui passe à travers ces choses-là, ça peut aider. »*

Persons with ID agreed that visual aids, such as images of sexual anatomy as opposed to drawings, and interactive activities would be a valuable supplement to discussions.

Front-line Staff. Front-line staff also reported a preference for the LSSL:RR program and the NGT. Reported benefits of the LSSL:RR program were the shorter length than other programs and the focus on topics of safety and respectful relationships. Another front-line staff reported that this program teaches persons with ID to make better choices and goes beyond information easily found on the Internet, such as how to form relationships:

> *« Je pense quand même que le contenu du (LSSL:RR) est de t'amener à faire des meilleurs choix. C'est plus difficile comme information à apprendre ça. Il y a bien des informations qui sont accessibles. (…) Donc l'information de base qu'on va leur dire,*

mettre un condom et tout ça, c'est sur l'Internet. Ce n'est pas sur l'Internet que tu vas trouver comment avoir des relations, des choses comme ça. »

This program went above basic notions of sexuality and matched the service agency's mandate by involving persons with ID. However, there were concerns around choosing persons with ID who have sufficient communication skills to facilitate the program: *« Si les pairs sont capables de transmettre le message ou l'information, ça peut être bénéfique »*.

As for the NGT, preferences were related to the increased involvement of persons with ID. One front-line staff specifically mentioned that it allows persons with ID to express their needs and desires, as well as what they would like to learn: *« J'aime le (NGT) dans le sens qu'ils nous expriment leurs désirs, leurs besoins, qu'est-ce qu'ils veulent apprendre. J'aime vraiment ça puis, peut-être avec ça, on peut personnaliser »*. They reported that the NGT facilitates communication between front-line staff and persons with ID; however, they reiterated the importance of having persons with ID make the decisions about their sexuality.

To improve the existing support, front-line reported wanting training on sexuality by involving an expert on the topic and training for persons with ID for them to learn socio-sexual skills:

P : « Ça serait intéressant de ramener les ateliers (pour le personnel) mais avoir quelqu'un qui se spécialise là-dedans. »

P1 : « Puis ça serait le fun d'avoir des groupes pour les personnes. Des ateliers une fois par semaine et des cercles sociaux puis des habiletés socio-sexuelles. Parce qu'il y a un manque. »

Front-line staff were divided on the content of the workshops and the number of sessions. One front-line staff working in non-residential services reported that only one workshop per year on basic sexual knowledge would suffice as external services are available for higher support needs:

> *« L'idée là-dessus c'est qu'on n'a pas assez de grands besoins pour être formé plus haut. Une fois par année, la base, ok. Plus que ça, c'est une formation qui, à mon avis, n'est pas nécessaire. Quelqu'un d'externe va venir nous aider au besoin. »*

Another front-line staff mentioned the need for multiple workshops to create familiarity and reduce embarrassment: *« Il a aussi d'être confortable plus qu'une fois. Tu sais parce que les personnes qui se rencontrent juste pour parler de leur sexualité, en bas de ligne, c'est un peu gênant »*. This could involve having groups for some persons with ID and one-on-one sessions for others: *« Faudrait qu'on ait des groupes, qu'on puisse avoir des groupes, ou du un-à-un dépendant de la personne, où on peut s'asseoir et faire ça avec les gens »*. They highlighted the importance of tailoring sexual education to participating persons with ID. Finally, front-line staff reiterated that having short and visual strategy to support sexuality would maintain attention and increase accessibility:

> *« Vu la capacité d'attention des personnes, plus c'est court, plus c'est synthétisé, plus c'est visuel, plus c'est – ça passe tellement vite. Le plus court, le plus visuel, je pense que ça passe plus. C'est plus facile parce qu'une image vaut mille mots. »*

Caregivers. Caregivers preferred both the LSSL: RR program and the NGT. The LSSL: RR was favoured by most caregivers because of the peer education component, which allows the program to be led by persons with ID. Caregivers expressed that peer education was closely related to the service agency's mandate.

For the NGT, caregivers would rather have an expert in sexuality lead the discussions to reduce discomfort: *« J'aimerais voir peut-être quelqu'un qui se spécialise en psychologie sexuelle. Comme ça, (pointe la chercheure), puis avoir des rencontres avec les individus (…) parce qu'ils peuvent être un petit peu plus confortables avec établir une relation »*. A caregiver in focus group A reported that the NGT would not be feasible without tailoring it to the needs and level of comprehension of participating persons with ID:

> *« Je ne suis pas certaine que ça fonctionnerait. Faudrait évaluer les besoins, le niveau de compréhension de la personne qui participe. Faudrait l'adapter. Ça serait une bonne approche pour ceux qui sont en appartement. Dans le cas de personnes autistes, je dirais :* do it in pictures *»*.

Caregivers report wanting to be more involved in supporting the sexuality of persons with ID. One caregiver reported being consulted more frequently in the past; however, consultations were reduced by the agency due to financial restrictions: *« Avant, il y avait plus de rencontres avec les parents. Ça a été coupé pour des raisons financières »*. They reported wanting more resources (i.e., a resource booklet with common questions), training, and more open communication between them and the service agency. They would also like additional activities organized by the *Mouvement des personnes d'abord* (People First Mouvement) for persons with ID to develop friendships that are not only dances. For example, one caregiver reported that crowds and loud noises are problematic for some persons with ID. In terms of additional support, they would like a sexuality expert to meet persons with ID without having front-line staff and caregivers present. Additionally, caregivers would like to be involved following the consultations with the sexuality expert and being able to contact them as needed: *« C'est peut-être encourageant d'avoir quelqu'un qui est capable de gérer, puis de voir, et après*

ça consulter les parents ». Finally, caregivers suggested involving the *Mouvement des personnes d'abord* (People First Mouvement) to facilitate the implementation of the chosen strategy: *« Ils pourraient avoir plus d'ateliers puisqu'ils ont le Mouvement des personnes d'abord. Il pourrait y avoir une session sur la sexualité »*.

Summary

Focus groups revealed critical information about existing services provided by the service agency to support the sexuality of persons with ID. For example, the service agency did purchase a sexual education program: the *Sexo-trousse* (Sex-Guide) (Lemay & Belley, 1996). However, front-line staff rarely used this program and was no longer feasible due to recent technological changes (i.e., involving acetates for projectors and VHS tapes). Support towards sexuality was also passive. First, the service agency organized many social activities for persons with ID, but their focus was on building friendships. As for sexual knowledge and behaviours, front-line staff only intervened when requested by persons with ID or when inappropriate behaviours were presented. Furthermore, front-line staff did not operate under any specific policies or procedures related to sexuality. They also reported not receiving any formal training, which may have caused inconsistencies in the support provided.

In terms of implementing change within the service agency, most stakeholders recommended a mixture of the identified strategies, with a preference for the LSSL: RR and NGT. There is a consensus that the strategy's format and content should be tailored to the participants. For example, stakeholders reported that some persons with ID would prefer basic sexual knowledge (e.g., contraception, sexual differences) and that others would prefer sexual education beyond the basics (e.g., sexual relationships and communication). For this reason, front-line staff and caregivers highlighted the importance of assessing the needs of persons with

ID. Stakeholders also mentioned a preference for a shorter strategy, including visual aids (real images and videos) and activities.

Finally, the staff talked about the need for external expertise to support change. They reported missing the relevant expertise and would seek out external professionals or workshops for additional support. This emphasizes the relevance of IKT interventions to support the sexuality of persons with ID. This will be further explored in the overall discussion of the chapter in subsection 4.

2. Stakeholder Dialogue

In this sub-section, the knowledge, experiences, and preferences from Section 1 were consolidated in a detailed evidence brief. We describe the format and content of the evidence brief. This brief acted as supporting documentation for a large group discussion among some members of the focus groups and new stakeholders (i.e., senior management). We also explore how various stakeholders engaged in this discussion to inform the implementation of change within the service agency.

Introduction

Knowledge from scientific literature may help service providers make decisions on how to best support persons with ID. For this reason, it is essential to identify, summarize and translate this knowledge to service providers in practical formats (Grol, Wensing, et al., 2013). To facilitate disseminating knowledge on the strategies with the highest level of evidence to support the sexuality of persons with ID, strategies identified in the scoping review were made available to service providers in the form of an evidence brief. Evidence briefs, also known as policy briefs, aim to convince primary stakeholders to take action to address a high-priority issue

(World Health Organization, 2011). These briefs ensure that decisions related to an issue are informed by scientific literature (World Health Organization, 2011). They provide a description of the problem, a summary of the best available evidence on the extent of the problem, a description of interventions to address the problem, and potential barriers to implementing these interventions (Lavis et al., 2009). The evidence brief was developed according to evidence briefs previously used in health research (World Health Organization, 2011). By packaging information on a specific issue into one document, relevant stakeholders may quickly identify critical features and scan large bodies of scientific information (Lavis et al., 2009). We created a user-friendly lay language document with details on the five identified strategies from the scoping review, potential implementation considerations, and a summary of the focus group findings. The evidence brief was used to support a group discussion with various stakeholders.

When discussing potential improvements to practices, it is crucial to improve interactions and communication among various stakeholders (Clemmer et al., 1998; Firth-Cozens, 1998). One way to enhance collaboration is to involve all relevant stakeholders in discussions on priorities, barriers, and facilitators for implementation in the target setting (Clemmer et al., 1998). This was achieved using a structured discussion format known as a stakeholder dialogue with persons with ID, caregivers, and agency personnel.

Using the stakeholder dialogue, we aimed to identify or create a strategy to implement informed by the evidence, previous consultations, and discussions with participants to better respond to the needs and resources of the service agency. Specifically, our objectives were to 1) review the content of the evidence brief, 2) discuss implementation considerations, 3) select, tailor, or combine the five strategies identified in the scoping review, and 4) develop an implementation team.

Method

Recruitment of Participants. We recruited participants using the same strategy with the advisory committee as for the focus groups. Stakeholders included front-line staff, persons with ID, caregivers, and senior management from the service agency. Participants were included if they: 1) were over 18 years of age, 2) currently provided or received services from the target agency, and 3) had sufficient communication and comprehension skills to provide consent and participate in the discussions. The advisory committee members distributed the invitation letters and consent forms. These documents contained the objective of the stakeholder dialogue, information on the anonymity of responses, protection of the data collected, and the research team's contact information.

Participants. A total of 22 stakeholders participated in the dialogue. This included 3 front-line staff, 16 senior management (6 directors, 7 supervisors, and 3 admins), 1 caregiver, 1 person with ID, and the primary researcher. Participant age ranged from 28 to 60 years of age. Most participants identified as female (n = 20), whereas only 2 participants identified as male. Agency personnel had begun providing services within the agency as early as 1991, and as late as 2017.

Procedure. The stakeholder dialogue structure was adapted from a template by the SURE Guide of the World Health Organization (World Health Organization, 2011). A script for the stakeholder dialogue is available (see Appendix F).

The dialogue occurred in a board room at the service agency. Participants were seated around a large table in no specific order as their collaboration was crucial for a successful

stakeholder dialogue. A senior researcher moderated the dialogue, ensured that all stakeholders contributed to the decision process, constructively challenged viewpoints using information from the evidence brief, and kept the discussion focused on the task at hand (World Health Organization, 2011). The primary researcher's role in the dialogue is to use information from focus groups to help with stakeholder indecisiveness in choosing interventions of similar levels of evidence. Members from the service agency chose the discussion topics (i.e., barriers to target) and ultimately decided which strategy best fits their needs, mandate, and allocation of resources.

Materials. An evidence brief was distributed two weeks before the stakeholder dialogue by the advisory committee. This evidence brief contained knowledge on barriers for service agencies when supporting the sexuality of persons with ID, five strategies to address these barriers identified in a scoping review, and implementation considerations from research evidence and consultations with various stakeholders.

The format of the evidence brief was adapted from existing guidelines from the SURE Guides for Preparing and Using Policy Briefs (Lavis et al., 2009). The primary researcher consulted existing outlines, work plans, and templates for evidence briefs and published evidence briefs (World Health Organization, 2011). These briefs typically start with a preface detailing the report's purpose, structure, preparation, and limitations. The following section is an explanation of the problem the report is trying to address. This is followed by various options to address the problem and implementation considerations. The report ends on the next steps for stakeholders to discuss the report.

The content of the evidence brief was informed by the scoping review and consultations with key stakeholders (i.e., persons with ID, front-line staff, and caregivers). The review and consultations are presented in the previous section. This information was combined into one 30-page document to inform decision-making for various stakeholders (e.g., senior management, front-line staff, persons with ID, and caregivers) in the following study step. It included a first page outlining the aim, how to use the brief, the structure, how it was developed and limitations. A two-page summary followed this with an overview of the issue, a brief description of the five strategies from the scoping review, four critical considerations for implementation, and a summary of all focus groups. The full report included scoping review results on barriers to supporting the sexuality of adults with ID, a description of the five strategies identified to address critical barriers, implementation considerations, and a summary of focus group findings per stakeholder group. We supplemented the evidence brief with detailed descriptions of the five strategies identified in the scoping review. The final evidence brief was reviewed by a senior researcher and the advisory committee and adapted accordingly. See Appendix D for additional information on the evidence brief.

This evidence brief contained a large sum of knowledge from evidence-based and informed research. This document did not intend to favour one strategy over another or end discussions on supporting the sexuality of persons with ID. Instead, this document informed all relevant stakeholders of the identified knowledge and supported discussions among stakeholders of varying experience and expertise.

Data Analysis. The stakeholder dialogue was audio-recorded and transcribed verbatim. The primary researcher analyzed data using a pre-structured case summary approach described in Chapter 3, Section 2.1. See Appendix E for the outline created for this analysis.

A short self-report questionnaire was also administered following the first half of the dialogue and at the end. The questionnaire gathered feedback on the usefulness of the evidence brief and the clarity of its content. The questionnaire also sought feedback on the evidence brief and the stakeholder dialogue and whether they were conducive to decision-making on implementing a strategy (see Appendices G and G1). Furthermore, a visual aid was developed to assist persons with ID in answering the questionnaire (view Appendix G2).

Findings

Findings are organized according to three major themes identified from the pre-structured summary outlines. First, we describe how stakeholders engaged in the IKT intervention using the evidence brief and the stakeholder dialogue. Second, we report on the strategies of interest. Third, we identified implementation considerations discussed by those participating in the dialogue.

Methods to Engage Stakeholders. An evidence brief and a stakeholder dialogue were used to support stakeholders in engaging in the IKT intervention.

The evidence-brief was designed as a source of information to support decision-making by stakeholders of varying experiences and priorities. It contained a large amount of information on the targeted issue, a detailed description of the five strategies from the scoping review, and summaries of focus group findings. Unfortunately, this document was not distributed as intended to participants before the dialogue. Only a handful of participants read the evidence brief. Of those who read the evidence brief and provided feedback, we received positive feedback on the format and the content of the evidence brief. One caregiver who looked over the evidence brief during the dialogue commented that the document was a great starting point but hard to

understand. Generally, participants were unaware of the five identified strategies that could be implemented or focus group findings. For this reason, the first part of the dialogue, involving senior management, focused on knowledge sharing rather than decision-making.

The stakeholder dialogue was designed to allow stakeholders of varying experiences and expertise to participate in choosing the strategy to implement. Not all participants actively engaged in discussions during the dialogue. First, the dialogue format may not be accessible to those unfamiliar with the content and context. For example, when a participant with ID commented, it appeared to be off-topic (i.e., related to their workplace), and no participant could continue the conversation beyond providing validation. Furthermore, the lack of knowledge on the evidence brief and its content kept discussions with senior management around previous study findings rather than implementation.

Second, caregivers and persons with ID's role in the dialogue, as representatives of their focus groups, was to provide additional input on focus group findings. However, there were no opportunities for them to provide additional knowledge. One caregiver commented in the questionnaire that discussions were high-level, grouping various aspects to consider and past discussions that they did not know about. Interestingly, there were no disagreements during the stakeholder dialogue. Participants did express various experiences and opinions; however, all participants agreed with the knowledge shared by others.

Finally, the dialogue did not lead to the expected outcome, meaning that a specific strategy for implementation was not identified. Instead, an implementation team and plan were established to determine what strategy to implement within the agency.

Participation in the self-report questionnaire was meagre (n = 4). Three of those participants were advisory committee members, and the fourth was a caregiver who participated in a focus group. All participants were given the self-report questionnaire at the break; however, most participants left the dialogue after the first hour (i.e., senior management to attend another meeting, persons with ID and caregivers as they were not invited to continue the discussion). Little information could be extracted from the questionnaire given the low response rate and the lack of exposure to the evidence brief before the stakeholder dialogue.

Strategies of Interest. Stakeholders had varying strategies of interest. Senior management kept discussions at a very high level. First, senior management identified high-level actions to support the sexuality of persons with ID. For example, one participant commented that the agency could further create and build on existing evidence that could support the agency:

> *« Je veux certainement dire aux membres des équipes que de rédiger, de nous appuyer sur les écrits par rapport à d'autres politiques existantes qui pourraient nous aider, ça on peut le mettre dans notre plan de travail. C'est faisable et oui, c'est un manque ».*

Senior management also noted the importance of providing basic sex education for some, but also to go beyond that for those who might need support in relation to sexual identity:

> *« D'une part, ce que j'entends des personnes sont des aspects très techniques de la chose: masturbation, menstruation et tout ça. Mais qu'est-ce qu'on fait avec les personnes qui sont en déficience et qui sont en recherche identitaire au niveau sexuel? ».*

Senior management, caregivers and persons with ID only participated in the first hour of the discussion. The remaining participants (i.e., advisory committee, front-line staff, and supervisors) also identified strategies of interest. First, discussions mirrored what was shared by

senior management in the first hour of the discussion. Participants expressed a desire for a strategy that addressed sexual identity as well as basic sexual knowledge. They also expressed a desire for staff training, especially on personal influences on the type of support provided (e.g., culture, religion, age, etc.). Second, one key discussion topic was the type of training provided to persons with ID and front-line staff. One participant expressed a desire for staff training which would then help them support persons with ID: *« Donner une formation au personnel qui va ensuite l'appliquer auprès des personnes. Je trouvais ça intéressant d'y aller de façon parallèle »*. The primary researcher suggested involving persons with ID. For example, they could use the Nominal Group Technique elements to make discussions more accessible to persons with ID. One participant expressed concerns that, like earlier in the dialogue, persons with ID would not understand the topic at hand, whereas another participant highlighted concerns with the privacy of the information shared: *« En tant qu'intervenante, c'est que s'il y a des personnes, il y a des choses que je ne dirai pas »*. Third, the following discussions were on the content of the strategy that could be implemented. One participant suggested using preferences shared in focus groups with persons with ID to inform the development of the strategy: *« Comme on connaît les intérêts des personnes, on peut cibler déjà 6-7 points et faire une formation juste avec ça »*. Another participant continued to say that, in preparation for the first implementation team meeting and to inform content choice, the primary researcher should extract critical topics of interest from the focus groups with persons with ID:

> *« Ça serait une très bonne idée pour notre première rencontre que tu nous sortes c'est quoi exactement les points qui sont ressortis le plus. On pourrait en cibler (…) les trois prioritaires qui reviennent et on travaillerait sur un plan pour ça, aller chercher quelqu'un d'externe, aller chercher une formation x. »*

Implementation Considerations

Various implementation considerations were identified. Senior management expressed that implementing research evidence is an overwhelming challenge that could be addressed through progressive implementation of change: *« Quand on parle d'une démarche au niveau de la recherche, c'est gros ça. Le défi va être de voir comment [l'organisme] peut travailler par phase d'implantation. C'est graduellement, progressivement pour être capable de suivre »*. Another participant found that sexual education alone wasn't sufficient to support the sexuality of persons with ID. Persons with ID would need someone available to support them and continue conversations on sexuality: *« J'aime l'idée des programmes mais ça ne peut pas se terminer là. Il faut s'assurer que quelqu'un est toujours disponible pour continuer à supporter, à discuter et à pousser »*. This was to ensure learning retention and successful long-term implementation. Finally, cultural influence was identified as a key barrier to supporting sexuality within the service agency. For example, one participant mentioned standardizing how support is provided to address personal influences: *« Souvent, on ne va pas interpréter la sexualité de la même façon selon la culture ou même selon les croyances religieuses. Comment est-ce que vous pensez faire si vous voulez établir une intervention standardisée? »*. Another participant continued to highlight the importance of staff training to address this barrier: *« De là l'importance d'avoir un système d'information homogène pour qu'on puisse dire voici les valeurs au niveau de l'organisation, voici les besoins de formation. (…) Il faut que [l'employé] soit capable de s'éduquer pour éduquer la personne »*.

Those who continued the discussion past the first hour had concerns about including persons with ID of varying levels of support. For example, one staff member mentioned that some persons with ID are non-verbal or require high levels of support in residential services. It

may be hard to provide sexual education to this group: *« Au niveau résidentiel, [on] a beaucoup de personnes non-verbales. Comment faire l'éducation d'une personne non-verbale ou de quelqu'un qui a une déficience très profonde? »*. Another participant highlighted that staff training could address this :

> *« Si le personnel est sensibilisé à l'expression des besoins sexuels de la personne qui a une déficience plus profonde, le personnel va offrir des moyens. Ce que la personne n'est pas capable d'exprimer verbalement, elle s'exprime autrement. (…) Si l'intervenant est fermé, il n'entendra pas le message »*.

Participants mentioned varying needs of persons with ID related to sexuality. Some persons with ID would like to know how to engage in various sexual activities and need more visual support, whereas others may not need to discuss this. They recommended doing a needs analysis to understand what specific knowledge persons with ID have before choosing a strategy. In the end, it was agreed upon that focus groups with persons with ID identified their knowledge and preferences towards sexuality. A final barrier was the implementation itself. To meet timelines for the dissertation, the implementation team would have to choose and potentially develop a strategy within four months. One participant expressed concerns with the expected workload and suggested focusing on critical topics discussed such as cultural influence and sexual identity to manage expectations:

> *« Veux, veux pas, on va avoir beaucoup de choses à faire. Comme on a beaucoup mentionné la culture et (l'identité) sexuelle, j'aurais l'attente qu'on irait vraiment à fond avec ça et de regarder comment former le personnel dans peu de temps »*.

Summary

Our overall objective for this study step was to discuss previous findings to inform the implementation of a chosen strategy. Although there were some challenges with distributing the evidence brief and the structure of the stakeholder dialogue, we were still successful in discussing key strategies for supporting the sexuality of persons with ID, identifying agency-specific implementation considerations, and creating an implementation team.

Stakeholders preferred strategies that would address the varying support needs of persons with ID, including basic sex education or support with sexual identity. Senior management also suggested actions that could be made independent from the study, such as revising existing policies and further use research evidence in practice. Other participants identified specific strategy elements that could be implemented, such as parallel training for both persons with ID and front-line staff. In terms of the content of choice, all stakeholders agreed that focus groups findings with persons with ID would inform which topics to prioritize.

Several implementation considerations were discussed. All stakeholders agreed that there was an inconsistency in providing support due to personal differences (e.g., culture, age, religion, etc.). They agreed that staff training could lead to consistency in support. Finally, all stakeholders had concerns about the scope of the study. Senior management suggested progressive, step-by-step implementation, whereas other participants recommended focusing on a handful of main topics. Additional information about the implementation team and the chosen strategy are discussed in the following section.

3. Implementation of Chosen Strategy

In this subsection, we provide details on developing the chosen strategy, which involved collaborating with a person with ID as a co-researcher to develop and facilitate two in-person

sexual education workshops. We also provide information on the experience of workshop participants and how this led to the online sexual education program.

Introduction

Barriers to the sexuality of people with ID have been well documented. Among these, people with ID have alarmingly higher rates of sexual abuse compared to the general population (Levy & Packman, 2004). In a nationwide study in Taiwan, people with ID were 2.7 times more likely to be victims of sexual abuse than the general population (Lin et al., 2009). In another study, prevalence rates of sexual abuse among persons with ID were estimated to be as high as 90% (Matich-Maroney, 2003). Research suggests that people with ID are at greater risk than the general population due to greater social isolation, dependency, absence of recognition of abuse, increased exposure to professionals, reduced boundaries (Plummer & Findley, 2012), and greater lack of sexual knowledge and sexual experiences than people without an ID (Ailey et al., 2003). Given the high vulnerability of people with ID to sexual abuse (Plummer & Findley, 2012; Thompson et al., 2014), it is especially difficult for policy makers and professionals working with people with ID to balance the right to consensual sexual expression with protection from abuse (Almack et al., 2009; Dukes & McGuire, 2009; Greenwood & Wilkinson, 2013; Johnson et al., 2002).

Persons with ID may also have low sexual knowledge. A study by Galea, Butler, Iacono, & Leighton (2004) revealed that persons with ID have limited knowledge of safe sex practices, including contraception and protection against sexually transmitted infections. Using the Sexual Knowledge, Experience, Needs Scale (SexKen), McCabe (1999) demonstrated lower sexual knowledge and experiences in persons with ID than in their non-disabled peers and greater negative attitudes towards sexuality. Reasons for lower sexual knowledge include difficulties in

learning and retaining information (Aunos & Feldman, 2002), and inadequate sexual education (McCabe, 1999) and information on the emotional and psychological aspects of intimate relationships (D. Thompson, 2001).

People with ID often want to become more knowledgeable about sexuality (Healy et al., 2009; Siebelink et al., 2006). The need for social, informational, and practical support for people with ID is indisputable (Ailey et al., 2003; Rushbrooke et al., 2014; United Nations, 2006). In this study step, our objective was to develop and implement a strategy to support the sexuality of persons with ID receiving support at a community-based service agency. Specifically, we describe two sexual education workshops, participants' experiences, and how these experiences led to developing an online sexual education program.

Method

Development of the Sexual Education Workshops. Multiple knowledge sources informed the development of a sexual education program: consultations with various stakeholders, credible sources, and collaboration with a person with ID.

Consultations with Relevant Stakeholders. Various stakeholders from the service agency chose the knowledge topics included in the sexual education workshops. First, focus groups were held with persons with ID. In these focus groups, persons with ID reported topics that would best fit their preferences and needs. Persons with ID were divided according to their perceived sexual education needs. Some had preferences for topics related to basic sexual knowledge such as sexual anatomy, differences between gender and sex, and contraception, whereas others preferred communication with a partner, diverse sexual practices, and supporting children.

Second, the implementation team, consisting of two persons with ID, three front-line staff, and two supervisors, reviewed the focus group findings. The primary researcher presented the findings during the first implementation team meeting. Each implementation team member was tasked with selecting the top three topics they preferred from the list of topics identified in the focus groups. Members proceeded to share their preferences. Discussions continued until consensus was reached. Three main topics were chosen for the sexual education workshops: sexual diversity, methods for protection, and prevention of sexual abuse. Implementation team members agreed that each workshop should focus on one of the chosen topics. The primary researcher developed two of these workshops, and the third was delegated to a community-based organization supporting survivors of sexual abuse in Ottawa (CALACS).

Credible Sources. The primary researcher consulted multiple credible sources when developing the content for the two sexual education workshops. These sources included the Ontario's Ministry of Education Sexual Education curriculum, revised in 2019, the World Health Organization, and Planned Parenthood. In addition to these sources, the primary researcher met with two community partners who provide sexual education: Planned Parenthood Ottawa and Venus Envy Ottawa. Planned Parenthood Ottawa is a not-for-profit organization offering education and services to support individuals in making informed choices about sexuality. Venus Envy Ottawa is a local sex shop and bookstore that also provides sexual education workshops.

Collaboration with a Person with ID. There were many discussions throughout the study on how the strategy would be delivered. As per the scoping review and focus group findings, the advisory team chose to involve a person with ID to develop the workshops. The research team hired them as a co-researcher and co-facilitator for both sexual education workshops. The

primary researcher met with the co-researcher twice a week for two-hour sessions at the University of Ottawa for two months.

The two sexual education workshops were in PowerPoint format. The initial slides were prepared by the primary researcher and reviewed by the co-researcher. The co-researcher revised the content for its relevance and accessibility (e.g., complexity, length, use of visual aids) by going through both presentations slide by slide. The co-researcher also agreed to provide real-life examples to support the presentation and facilitate activities during the workshops.

Workshop sessions were practiced several times a week to increase familiarity with the content and ensure that facilitation notes were sufficient to support the co-facilitator. The workshops were also presented to members of the research team and another team specialized in sexuality research for feedback.

Final Workshop Content. The final workshops were designed for both persons with ID and front-line staff to attend as equal learners. Each workshop was on different aspects of sexual health as chosen by the implementation team: sexual diversity and methods for protection. The first workshop included topics of sexual anatomy, protection (e.g., consent, personal limits, communication, respect of others, sexual identity (e.g., gender, sex, and sexual orientation), and diverse sexual practices. The workshop had word association activities with images of reproductive systems, a word cloud activity to identify different ways of obtaining pleasure, activities on consent, and social norms.

The second workshop included a review of content from the previous workshops, such as consent, communication, and respect for others. This was followed by another case study on inappropriate sexual behaviours. The remainder of the workshop was new content, including

contraceptive methods (i.e., oral contraceptives, injections, patches, IUD, sterilization, and barriers). It also included activities on myths about condoms, on how to choose a contraceptive method, on communicating with a partner about contraceptives, on sexually transmitted infections (i.e., protection from them, identifying them, steps to get tested), and a final activity on communicating with a partner about sexually transmitted infections.

Participants. Participants were included if they were currently receiving services (i.e., persons with ID) or if they currently supported a person with ID at the service agency (i.e., front-line staff). In the first workshop, there were 14 participants (7 persons with ID, 7 front-line staff). In the second workshop, all participants were new. A total of 5 persons with ID and 6 front-line staff (n =11) participated in the second workshop. It had been expected that participants from the first workshop would partake in the second as well.

Procedure. Both sexual education workshops were facilitated at the service agency one week apart. At the beginning of each session, the primary researcher explained the study, answered participant questions, and collected the signed consent forms. Participants were informed that discussions would be audio-recorded.

The final sexual education workshops were 2 hours and 30 min each. The primary researcher and the co-researcher began each workshop with a short introduction, the learning objectives related to the workshop, and the agenda. Both workshops were organized in the same format. The facilitators presented content for approximately 45 minutes, including activities, then participants would take a 15-minute break. This step was repeated. Workshops would end with a shorter content presentation of about 15 minutes. A final 15 minutes were allotted to complete the self-reported questionnaires detailed below.

Data Collection and Analysis. All workshops were audio-recorded for quality improvement purposes. In addition to these recordings, the primary researcher, with the help of two undergraduate students[6], administered a short self-report questionnaire at the end of each session. The co-researcher also completed the questionnaire after the second workshop to provide their overall impressions. These questionnaires used a Likert-type agreement scale ranging from one to five. Participants could also provide qualitative feedback after each item. The purpose of the questionnaires was to gather feedback on participants' experiences and identify potential improvements to the workshops (see Appendix H). Furthermore, an undergraduate student (DL) conducted separate semi-structured interviews with the primary researcher and the co-researcher following the completion of the workshops. The objective was to gain insight into their relationship and experiences in developing and facilitation the workshops. These interviews were also audio-recorded.

All audio recordings were transcribed verbatim. Transcriptions and questionnaire data were entered in QSR NVivo 12 for analysis (QSR International Pty Ltd, 2019).

Findings

Findings are presented in three separate sections. First, we present the results from the questionnaires and describe the experiences of participants in each workshop. In the second section, we discuss the experiences of the co-researcher in the development and facilitation of the workshops. In the final section, we present an overview of the online tool developed to address feedback received by participants, the facilitators, and the advisory committee.

[6] DL and another psychology student who received trainings on supporting persons with ID and facilitating group discussions.

Experiences of Participants. All participants in the workshops completed the self-report questionnaire. One participant's data was removed as all fields except demographic information were left blank. The first workshop generated slightly more positive responses than in the second workshop for the included activities. Overall, the sexual education workshops were well received by workshop participants (see Table 3.5). There is additional information about the quantitative findings in Chapter 4.

Table 3.5 *Self-reported questionnaire for the sexual education workshops*

	Means, Range	
Statements and questions	Workshop 1 (N = 13)[a]	Workshop 2 (N = 12)
The workshop content was clear and simple to understand.	4.53, 4 − 5 (n = 13)	4.25, 3 − 5 (n = 12)
The workshop gave me new information about sexuality.	4.08, 2 − 5 (n = 13)	4.42, 4 − 5 (n = 12)
The scope of the content was appropriate.	4.27, 3 − 5 (n = 11)	4.25, 4 − 5 (n = 12)
The representation of persons with ID and front-line staff was beneficial during the workshops.	4.38, 4 − 5 (n = 13)	4.45, 4 − 5 (n = 11)
Examples were clear and simple to understand.	5, N/A (n = 13)	3.92, 4 − 5 (n = 11)
Discussions were clear and simple to understand.	5, N/A (n = 13)	4.45, 4 − 5 (n = 11)
The activities allowed me to practice what I learned during the workshops.	4.23, 3 − 5 (n = 13)	3.64, 3 − 5 (n = 11)
During activities, I had the opportunity to ask questions.	5, N/A (n = 13)	3.82, 2 − 5 (n = 11)

Note. Likert scale from 1= strongly disagree to 5 = strongly agree
[a]One participant was removed as all fields were left blank.

Qualitative feedback in the questionnaires highlighted several areas for improvement. In the first workshop, respondents enjoyed hands-on activities and visual aids (e.g., animations and images). For example, one person with ID reported enjoying the presentation of various sex toys

as they were not familiar with all of them: « *J'ai bien aimé quand ils ont montrés les jouets car je ne l'ai connaissait pas tous »*. However, participants also reported wanting more activities and having facilitators use body language to support activities (e.g., asking participants to raise their hands for a yes, pointing to their own body to show where the uterus is). Other improvements were to consider providing the workshop to caregivers and find a way for agency personnel to administer the workshop.

In the second workshop, all participants were new participants and thus had not been exposed to the content of the first workshop. We expected the same participants to attend both sexual education workshops. Furthermore, persons with ID in the second workshop had higher support needs than those in the first workshop. Building on concepts of the first workshop, the second workshop had a higher degree of abstraction and complexity. It may not have been suitable for persons with ID with high support needs. This had an influence on face validity which was reflected in the questionnaire. Respondents reported wanting to be included in the first workshop, having facilitators use simple language, include more images and videos, and target persons with ID with low support needs. Accessibility of the second workshop was an issue. One respondent, a front-line staff assisting a person with ID in the workshop, expressed wanting activities such as crafts to verify comprehension of those with high support needs: *« Je voudrais participer à mon niveau en coloriant avec une image appropriée pour vérifier ma compréhension »*.

Experiences of the Co-researcher. In this section, we present the experiences of the co-researcher in collaborating with the primary researcher to develop and facilitate two sexual education workshops.

Most of the workshop content was identified and developed before the involvement of the co-researcher. Their role in the development of the workshop was to revise the content to increase accessibility and relevance: *« J'ai donné beaucoup de mon avis pour qu'on puisse faire en sorte que le projet soit simplifié pour les personnes ayant une déficience intellectuelle ».* The co-researcher reported some challenges during collaboration. In one instance, the co-researcher felt overwhelmed by the amount of content they had to present and asked to be removed from the study. Through discussion with a senior researcher, we reached a solution. The co-researcher chose to reduce the amount of content allocated and focus on presenting activities and real-life examples. The co-researcher also reported challenges with memorizing content as the content was continuously changing as the workshops were being finalized. Furthermore, specific tasks in the workshop facilitation were considered too complex by the co-researcher, such as presenting the definition of various concepts or parts of sexual anatomy.

The co-researcher reported many benefits to their participation in the project. First, during the development stage, the co-researcher reported having some initial discomforts with the topic at hand. They reported being bullied in school by other kids about their sexual activity, making them very uneasy with the topic. However, the co-researcher became more comfortable talking about sexuality after the project:

> *« Je pense que ça va m'aider à développer encore plus de contacts peut-être plus tard, et ça risque de m'aider à me sentir plus à l'aise de partager avec les gens dans la communauté. »*

Following the project, the co-researcher also reported receiving informal positive feedback from members of the service agency. One agency personnel even suggested putting their experience in

the study on their CV. The co-researcher highlighted that their experience was important for the primary researcher to learn about working with persons with ID. Finally, they reported being very grateful for their experience due to the many benefits for their personal growth: *« Je désire remercier [Chercheures] pour l'expérience. Je suis certaine qu'à la longue, ça va m'aider à grandir, être plus mature et m'aider à accroître mes développements que j'ai acquis face à ce projet-là ».*

Description of the Online Sexual Education Program. We received informal feedback from advisory committee members following the completion of both workshops.

They indicated that workshops were well received and that front-line staff and persons with ID shared many positive comments in the days following each workshop. However, they also expressed concerns about how they would continue to offer these sessions. Members of the advisory committee revealed that providing sexual education workshops once was insufficient to support the sexuality of persons with ID. They expressed a desire to have the primary researcher continue facilitating workshops or to train other front-line staff to facilitate the program. Unfortunately, both options were not feasible within the context of the research study. The primary researcher suggested creating an online training tool or having the workshop entirely online without the need for facilitation.

In the six months following the completion of the workshops, the primary researcher combined both sexual education workshops and facilitation notes into an online program. This program consisted of two parts. Part 1 included learning modules on sexual anatomy, sexual identity and sexual practices. Part 2 included learning modules on consent, contraception, and prevention of sexually transmitted infections. Each module contained interactive activities using

mouse click and drag functions and text boxes to input answers. Furthermore, both parts concluded with activities to verify comprehension, which mirrored activities in each module.

The online program contained more information than the slides used to present the in-person sexual education workshops. However, this tool was developed using an online e-learning program with several accessible features such as compatibility with screen readers and speech-to-text, display on various devices (i.e., phone, tablet, or computer), and zoom. Using this e-learning program, it was possible to add images and animations to increase the accessibility of the information. Finally, anyone can access the program anytime, anywhere, and from any device.

The program was designed to be used by persons with ID or front-line staff. However, the accessibility features, simple language, and degree of complexity of the content make the program suitable for persons with ID outside of the target agency and caregivers. In sum, the online program further expands on the usability, feasibility, relevance, and applicability of the program than the in-person workshops.

Summary

Our objective for this study step was to develop and implement a strategy to support the sexuality of persons with ID. The two sexual education workshops were well received by participants, facilitators, and advisory committee members. However, several improvements were identified.

Improvements were on how to increase the accessibility of the workshops for persons with ID. These included having more images, videos, animations, and activities for persons with

ID. Furthermore, it was agreed upon that these workshops would need to continue being implemented.

The co-researcher reported challenges and benefits with their participation in this study step. Challenges were around the accessibility of the task of developing the workshops and memorizing content to facilitate them. The primary researcher had to change ways of working with the co-researcher to support their continuation in the study. Benefits of participation for the co-researcher were also identified. These included being more comfortable discussing sexuality and towards their sexuality, gaining new skills, and having the opportunity to expose a researcher to the reality of working with persons with ID.

Findings from this study step led to the development of an online sexual education tool. This tool addressed accessibility issues in the workshops and solved problems with the long-term implementation of sexual education. The tool may also be used by other francophone caregivers, service agencies, and persons with ID.

Through this type of practice change, service agencies may be better equipped to support the sexuality of persons with ID. This may reduce barriers towards the sexuality of persons with ID and, in turn, more fulfilling sexuality.

4. Discussion on the IKT Intervention

The objective of this section was to describe an IKT intervention aimed at supporting the sexuality of persons with ID. Throughout the intervention, stakeholders collaborated to create, share, and implement the knowledge on strategies to support the sexuality of adults with ID currently receiving services at the target agency. In the following discussion, we explore the level of knowledge of various stakeholders and changes in how we address the sexual support needs of persons with ID.

The IKT intervention brought together stakeholders with varying levels of knowledge on the sexuality of persons with ID and how to support them. Throughout the intervention, there were several indications that agency personnel may not have sufficient knowledge to support the sexuality of persons with ID. Furthermore, culture, attitudes, religion, and other personal characteristics had an influence on what agency personnel deemed normal. For example, several front-line staff expressed clear objections to the use of sex toys, especially toys for anal pleasure. However, sex toys are valuable supports for persons with ID who may experience decreased sensitivity, have physical disabilities limiting motor functions, or take medication affecting mobility (Lukkerz & RFSU, 2010). Agency personnel did not recognize the influence they had on persons with ID. One participant disclosed referring to a same-sex couple as friends. This misinterpretation has been previously documented (Lofgren-Martenson, 2004) and may undermine opportunities for individuals to develop their sexual identity (Evans et al., 2009). These examples highlight the need for training of agency personnel to support the sexuality of persons with ID (Evans et al., 2009; Rushbrooke et al., 2014; Swango-Wilson, 2008; Wilkinson et al., 2015).

Contrary to what was reported in previous research, persons with ID participating in this project were knowledgeable about sexuality. Previous studies indicated that persons with ID generally had low sexual knowledge and misconceptions about sexuality, especially about safe sex, including contraception and sexually transmitted infections (Galea et al., 2004; Healy et al., 2009; Lofgren-Martenson, 2012), sexual practices, and sexual relationships (Corona et al., 2016; Jahoda & Pownall, 2014). In this project, participants spoke of gender identity, sexual orientation, contraceptive methods, sexual practices beyond vaginal penetration, support during pregnancy, and legal rights related to parenthood. Interestingly, these topics were not limited to

discussions with persons with ID who have low support needs. Perhaps researchers need to change how they perceive the problem of low sexual knowledge in persons with ID. New sexual education programs should focus on a broader range of topics and involve members of the community who support persons with ID.

Sexual education may not only be required for persons with ID but also for agency personnel. First, the lack of agency personnel training and resources supporting sexuality is well documented (Chrastina & Večeřová, 2020). Second, agency personnel need to be aware of the knowledge gained by persons with ID participating in sexual education to provide advice or answer any questions they may have. In this project, this was a concern expressed by front-line staff that was addressed by providing sexual health workshops for both persons with ID and front-line staff in the same room. Frawley and Bigby (2014) identified the benefits of including a learning partner, such as front-line staff, in designing their sexual education program. These included making sense of the knowledge gained by participating persons with ID and supporting their development (Frawley & Bigby, 2014). Front-line staff should be involved in the sexual education of persons with ID as they nurture the person with ID's relationships with community members. Third, in this dissertation, persons with ID and agency personnel shared interests and misconceptions about sexuality. With careful considerations of these three factors, the implementation team recommended having workshops together for people with ID and front-line staff.

Persons with ID need to be involved in research for evidence-based practices and policies to reflect their lived experiences (Farmer & McLeod, 2011). In this dissertation, persons with ID contributed to knowledge creation in the project, which directly influenced the choice and

development of the implemented strategy. The exclusion of persons with ID would have led to a considerable loss of knowledge and possibly reduced the relevance of the implemented strategy.

This IKT intervention aimed to make research evidence more accessible to knowledge users. However, knowledge dissemination alone is not sufficient to ensure practice change. By studying processes beyond dissemination, researchers may better understand facilitators and barriers to knowledge translation in service agencies. This will be discussed in the following chapter.

Chapter 4 – Process Evaluation of an IKT Intervention to Support the Sexuality of Persons with ID

The dissertation had two main aims: 1) to conduct an IKT intervention on supporting the sexuality of persons with ID, and 2) to evaluate this intervention. This section focuses on the second aim and the contribution of this dissertation to previous knowledge on IKT. More specifically, we aimed to understand underlying KT processes in the community sector and the field of intellectual disability research. In this step, all knowledge created and translated from previous study activities was subject to evaluation.

Introduction

Reducing the gap between research evidence and practice is key to ensuring the effective implementation of strategies to support persons with ID receiving community support. Through the iterative knowledge translation process, research evidence is synthesized, disseminated, exchanged, and applied to improve Canadians' lives (Canadian Institutes of Health Research, 2016). Knowledge in this process is also tailored for specific contexts to support evidence-based decisions. However, research underutilization remains an issue in the community sector. Researchers argue that research underutilization may not only stem from a failure to disseminate findings but also from a mismatch between translated outputs and the needs of those who will benefit from these outputs (i.e., knowledge users) (Straus et al., 2013; Van De Ven & Johnson, 2006). For this reason, more researchers are recognizing the importance of involving knowledge users throughout the research process (Graham et al., 2018).

Persons with ID are often excluded from research due to assumptions that they are at risk of exploitation and harm because of challenges with obtaining informed consent (Feldman et al., 2014; McDonald & Kidney, 2012). Instead, caregivers and professionals often act as proxies to speak on behalf of persons with ID. However, previous research has shown that information provided by proxies is not always accurate (Cobigo et al., 2009; Golubovic & Skrbic, 2013). The lack of involvement of persons with ID in research that concerns them may be explained by various factors. ID research is an emerging field; perhaps research evidence is not yet available to translate. It is also possible that this lack of evidence is due to challenges in involving persons with ID in research. Finally, previous knowledge translation studies may not have been accessible to persons with ID.

Persons with ID's involvement in knowledge translation research could increase using a different approach. For example, integrated knowledge translation (IKT) goes a step beyond traditional knowledge translation by engaging knowledge users early into the research process, as early as developing a research question (Graham et al., 2018). This increased collaboration shifts researchers' and knowledge users' roles to equal experts who provide different perspectives on the same issue (Davies et al., 2008). Ensuring an exchange of information between stakeholders, identifying information that is lacking, and having a research liaison working with community organizations are all strategies common to collaborative methods such as IKT that facilitate knowledge translation with persons with ID (Shooshtari et al., 2014). However, there is a lack of research on knowledge translation, including persons with ID (Martin et al., 2010; Shooshtari et al., 2014). Further research is needed to evaluate knowledge translation processes used in the community sector to inform policy and practice changes leading to better outcomes for persons with ID (Martin et al., 2010).

Process evaluation may be used to determine if a knowledge translation intervention was delivered as intended, if the target subjects were exposed to the intervention, and understand the experiences of those exposed to the intervention (Hulscher et al., 2013). Process evaluation may also inform the feasibility and applicability of an intervention to implement change (Hulscher et al., 2013). This evaluation method was chosen as it is commonly used in small-scale improvements projects (Hulscher et al., 2013), and it informs researchers of potential adjustments needed to a newly developed strategy (Benger & Pearce, 2002).

This study step aimed to answer questions about the feasibility and fidelity of an IKT intervention in a community-based service agency. We described how the IKT intervention was developed, implemented, and experienced by stakeholders through an in-depth analysis of how

different stakeholders collaborated to translate knowledge into practice. The study addressed the following three questions:

1) Were the steps of the IKT intervention completed as intended?

2) What were the facilitators and barriers of the IKT intervention, as perceived by the stakeholders involved?

3) What were the decision-making processes, how were decisions made, and how did this further the IKT process?

Method

Context

In a partnership between an academic institution and a community-based service agency offering various supports (e.g., leisure, residential, employment) to adults with ID, the primary researcher undertook an IKT intervention on supporting the sexuality of adults with ID.

The study's general aim was to identify evidence-informed practices to support the sexuality of persons with ID, inform decision-making for implementing this knowledge, and how, in turn, this knowledge could support the sexuality of adults with ID receiving services from a community-based service agency. The targeted service agency is the only service agency supporting persons with ID in Ontario, Canada, which offers its services exclusively in French. Thus, all research evidence for the IKT intervention was for a linguistic minority.

Description of the Intervention to be Evaluated

The following paragraphs provide an overview of an advisory committee's development and the first six steps of the IKT intervention.

Advisory Committee. The primary researcher developed an advisory committee consisting of service agency personnel with different agency roles. This advisory committee ensured the coordination of study activities through communication with stakeholders, sharing documentation (Kotter & Rathgeber, 2006) and providing practice-based knowledge. The agency's primary contact chose members that consisted of supervisors and front-line staff from various services offered at the agency. Advisory committee members met monthly throughout the IKT intervention. Meetings took place in person and lasted one hour. Decisions were made through discussion to reach a consensus. The researcher's role was to expose scientific evidence that could guide implementation. Committee members made decisions, and the researcher proceeded with the directions of the group. If the committee could not achieve a consensus, the researcher implemented the decision held by most members.

Development of a Proposal for Change. The first step of the Implementation of Change model (Grol, Wensing, et al., 2013) was to develop a feasible proposal for change. The primary researcher conducted a scoping literature review to establish the current state of knowledge on the barriers that service agencies face when supporting the sexuality of adults with ID, possible interventions to address them, and implementation considerations. The review method and its findings are reported in Section 3, Chapter 1. The review included OVID (PsycInfo), ProQuest, and Academic Search Complete databases for papers published from 2000 to August 2018. The search strategy included broad terms related to intellectual disability and sexuality. Articles were included if they: (1) were published in English or French; (2) were published between 2000 and 2018; (3) in which the study explores strategies to support the sexuality of adults with ID (using any study design). Included articles were subject to a quality assessment to establish each

strategy's level of evidence mentioned in the articles. Additional information about the review process is found in Chapter 3, Section 1.

Analysis of Actual Performance. Following the development of a proposal for change, current practices were reviewed and assessed to determine the most significant deviations from optimum practices (Grol, Wensing, et al., 2013). Persons with ID currently receiving services from the service agency, front-line staff and caregivers participated in focus groups. The advisory committee recruited participants through purposive sampling. The focus groups identified if strategies identified through the scoping review applied to the study's context and how they could be tailored to meet stakeholders' needs. Thus, focus groups identified targets for change from the participants' perspectives by asking them to reflect on existing support towards the sexuality of adults with ID currently receiving services from this agency.

Furthermore, the input of persons with ID, front-line staff, and caregivers was gathered on the implementation of five strategies to support sexuality identified through the scoping review. Each stakeholder group (i.e., persons with ID, front-line staff, and caregivers) participated in separate focus groups. Unlike stakeholders, persons with ID participated in a series of three focus groups. Focus groups were split into three weekly sessions: each focused on a different question. Focus groups lasted from 45 minutes to one hour and were conducted at the service agency. For additional information on focus groups, refer to Chapter 3, Section 1.

Problem Analysis and Selection of Strategies to Change Practices. The problem analysis aimed to understand all stakeholders' potentially varying goals and interests before planning the implementation of a strategy (Grol & Wensing, 2013).

Scoping review and focus groups findings were translated into an evidence brief to be distributed within the service agency in preparation for this step. An evidence brief is a document highlighting a targeted issue and possible strategies to address this issue. For this dissertation, the evidence brief was developed to inform decision-making for diverse stakeholders in the following study steps. Existing guidelines from the SUPPORT Tool for Preparing and Using Policy Briefs (Lavis et al., 2009) informed the evidence brief's development. The first page of the brief outlined the aim, use, structure, and limitations. A two-page summary followed, which contained each part of the brief, including the problem, possible interventions, and implementation considerations. The full report included the scoping literature review results on service agencies' barriers when supporting the sexuality of adults with ID, five interventions to address critical barriers, and implementation considerations. Focus group findings were added as a supplement to the evidence brief to contextualize scoping review findings and provide key stakeholder input for decision-making. The method employed to develop the evidence brief is described in Chapter 3, Section 2.2.

Senior management of the service agency and participants from the focus groups (i.e., persons with ID, front-line staff, and caregivers) were invited to participate in a stakeholder dialogue. This dialogue is a structured discussion among stakeholders on findings from an evidence brief (World Health Organization, 2011). This structured dialogue was instrumental in generating insight and action from various stakeholders affected differently by decisions on supporting the sexuality of persons with ID. In preparation for this step, the evidence brief was sent to the advisory committee for further distribution to participants two weeks before the dialogue. The stakeholder dialogue lasted half a day, with senior management only participating

in the first hour and the remaining participants in the following three hours. There is additional information about the stakeholder dialogue in Chapter 3, Section 2.2.

A senior researcher moderated this dialogue. The primary researcher aimed to use the scoping review and focus group findings to help stakeholders choose a strategy to implement. The stakeholder dialogue informed the selection of an implementation team. The implementation team consisted of advisory committee members with two front-line staff, one supervisor and two persons with ID. The implementation team met monthly in person at the service agency. Each meeting lasted 2 hours. Participants chose the discussion topics (i.e., the barrier to target) and ultimately decided which strategy best fit their needs, the agency's mandate, and resource allocation.

Development and Implementation of a Strategy. In this step, the implementation plan is developed, tested, and integrated into routine support (Grol, Wensing, et al., 2013). The implementation team chose a strategy to implement, which resulted in two sexual education workshops for persons with ID and front-line staff. The first workshop covered sexual anatomy, diverse sexual practices, and consent, whereas the second workshop provided an overview of the first workshop and covered contraception and sexually transmitted infections. Participants in these workshops included persons with ID and front-line staff as independent participants. The front-line staff's role was to attend the workshops as learners and not to support participating persons with ID.

Each workshop lasted two hours and 30 minutes and was provided one week following the other. More information about the implementation and the sexual education programs are in Chapter 3, Section 2.3.

The primary researcher initially developed these workshops. The primary researcher developed the workshops' content based on the implementation team's recommendations and notes from the stakeholder dialogue. This content was supplemented by reputable sources for sexual education, such as the Ministry of Education of Ontario, Canada, the World Health Organization, and Planned Parenthood (Ontario Ministry of Education, 2015; Planned Parenthood, 2021; World Health Organization, 2021). In the next step, the research team hired a co-researcher with an ID to develop and co-facilitate the workshops. The co-researcher received services from the targeted service agency, thus understanding the targets and context in which the workshops would occur. The primary researcher met weekly for two-hour sessions over the following two months with the co-researcher to review workshop content. The co-researcher contributed by increasing the accessibility of the information provided (e.g., shortening, format changes), and improving the applicability and credibility of examples and activities used in the workshops. Once workshop content was agreed upon, the primary researcher assisted the co-researcher in preparing to deliver the program by dividing workshop content to be presented, explaining workshop content and activities, and practicing the presentation.

Process Evaluation

From this point forward, we describe the evaluation method used to evaluate the IKT intervention mentioned above. In the last step of the Grol & Wensing Implementation of Change model (2013), the intervention is subject to evaluation and adapted accordingly. Process evaluation was used to determine what aspects of the IKT intervention were delivered as intended, appraise feasibility, and describe the experiences of those exposed to the intervention. Specifically, we aimed to determine critical facilitators and barriers to IKT in the participating community-based service agency. The primary researcher conducted the process evaluation for

each step of the IKT intervention, from completing the scoping review to implementing the strategy.

Participants. Participants consisted of diverse stakeholders for each study step (see Table 4.1 for more information). Stakeholders included persons with ID, agency personnel (e.g., front-line staff, supervisors, managers, and directors), and caregivers (family members and foster home caregivers). The advisory committee recruited participants for each study step through purposive sampling. Included participants were persons with ID receiving services from the agency, caregivers supporting a person with ID receiving services, or were staff employed by the service agency.

Table 4.1 *Sample size for each study activity and per session*

Study Activity	Number of Participants		
	Persons with ID[a]	Staff	Caregivers
Advisory Committee	N/A	4	N/A
Focus Group A			
Session 1	7	8	6
Session 2	6	N/A	N/A
Session 3	7	N/A	N/A
Focus Group B			
Session 1	5	12	2
Session 2	4	N/A	N/A
Session 3	4	N/A	N/A
Stakeholder Dialogue	1	20	1
Implementation Team	2	6	N/A
Sexual Education Workshops[b]			
Workshop 1	7	7	N/A
Workshop 2	5	6	N/A
Process Evaluation Questionnaires			
Stakeholder Dialogue		3	1
Workshop 1	6	7	N/A
Workshop 2	5	6	N/A

[a]Persons with ID participated in a series of three focus groups, when only one meeting occurred for staff and caregivers participating to focus groups.
[b]Different participants participated in each workshop.

Data Collection.

Intended Versus Actual process. The primary researcher established the intervention's fidelity, the degree to which the intervention was developed as intended, by developing a logic model for the intended IKT intervention (see Figure 2.1). This model described the resources (inputs), intended study activities, potential outputs and outcomes, and their connection. The primary researcher shared the logic model with the advisory committee before study activities for revisions and guided the evaluation of the IKT intervention throughout the study.

Barriers and Facilitators to Implementation. The primary researcher established the barriers and facilitators to the implementation of the IKT intervention using various methods (see Appendix I). The primary researcher participated in all study activities and took notes from the advisory committee and implementation team meetings. In addition to these notes, the primary researcher noted observations from participant behaviours throughout the focus groups, the stakeholder dialogue, and the sexual education workshops. During the scoping review, the primary researcher kept notes of facilitators and barriers to conducting the review and extracting information from the chosen articles to create the evidence brief. The primary researcher also had key discussion notes on a whiteboard to help member checking at each focus group's end. Participants were asked if these critical messages were representative of their discussion and whether they needed to be adapted. The primary researcher adapted key messages accordingly. All focus groups, the stakeholder dialogue, implementation team meetings, and the two sexual education workshops were audio-recorded using two separate devices. The primary researcher transcribed these recordings verbatim.

Undergraduate students took notes in the focus groups (n = 1), the stakeholder dialogue (n = 2) and the sexual education workshops (n = 2) and recorded participant reactions and interactions. Following each sexual education workshop, undergraduate students helped collect information for the questionnaires by assisting participants with ID and answering potential questions. Undergraduate students received a one-hour training session with the primary researcher on identifying essential information not captured by audio recordings (i.e., participation, non-verbal signs). The primary researcher trained undergraduates who participated in the sexual education workshops to support persons with ID in completing the questionnaire.

The primary researcher administered a self-report questionnaire to all participants following the stakeholder dialogue and each sexual education workshop's implementation. The co-researcher also completed a self-report questionnaire following the last sexual education workshop. The questionnaire included 5-point Likert-scale items and focused on the perceived barriers and facilitators of the IKT intervention. For additional information on the structure of the questions for the stakeholder dialogue or the implementation, see Appendices H and H1.

The process evaluation included an additional step. An undergraduate student (DL) from the research team conducted two separate 1-hour semi-structured interviews with the primary researcher and the co-researcher. These interviews gathered the experiences of working collaboratively in developing and facilitating the two sexual education workshops.

Participants' Experiences. We determined the experiences of those exposed to the intervention by exploring participants' views on which intervention elements were most effective and potential improvements. We also explored how different stakeholders interacted over time to make decisions. The self-administered questionnaire mentioned above contained questions on the extent of participation and experiences in preparing for the stakeholder dialogue using the

evidence brief, experiences during the dialogue, and experiences when participating in each sexual education workshop. A final questionnaire was added to determine the co-facilitator's experiences when developing and administering the two sexual education workshops.

Data Analysis.

Intended Versus Actual. The primary researcher's record of deviations and similarities in study activities led to an actual logic model. The actual logic model was compared to the intended logic model to assess whether the IKT intervention was completed as intended.

Feasibility of the Intervention. The thematic analysis described below was used to establish the feasibility of the IKT intervention. The primary researcher imported all transcripts, meeting notes, and memos into QSR NVivo 12 (QSR International Pty Ltd, 2019). Data were analyzed using descriptive thematic analysis. Steps for conducting the thematic analysis included: 1) familiarizing oneself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, and 5) defining and naming themes (Braun & Clarke, 2006). Initial coding was adapted throughout the steps of analysis (Holloway & Wheeler, 2013). Then, focused coding determined which initial codes were most significant and examined the initial codes' adequacy in explaining the data. Categories synthesized the data and organized concepts marked by similar traits. Then, these were grouped into themes to develop an understanding of the relationships between and within categories. The primary researcher grouped emerging themes to answer the process evaluation questions. One reviewer developed the coding strategy, coded all relevant data, and generated themes. A senior researcher audited the coding method, and the organization of themes updated accordingly.

Throughout the analyses, memos were written to help facilitate coding. The primary researcher calculated means for Likert-scale items of the self-report questionnaires and summed total scores. Open-ended responses were analyzed using thematic analysis (as described above).

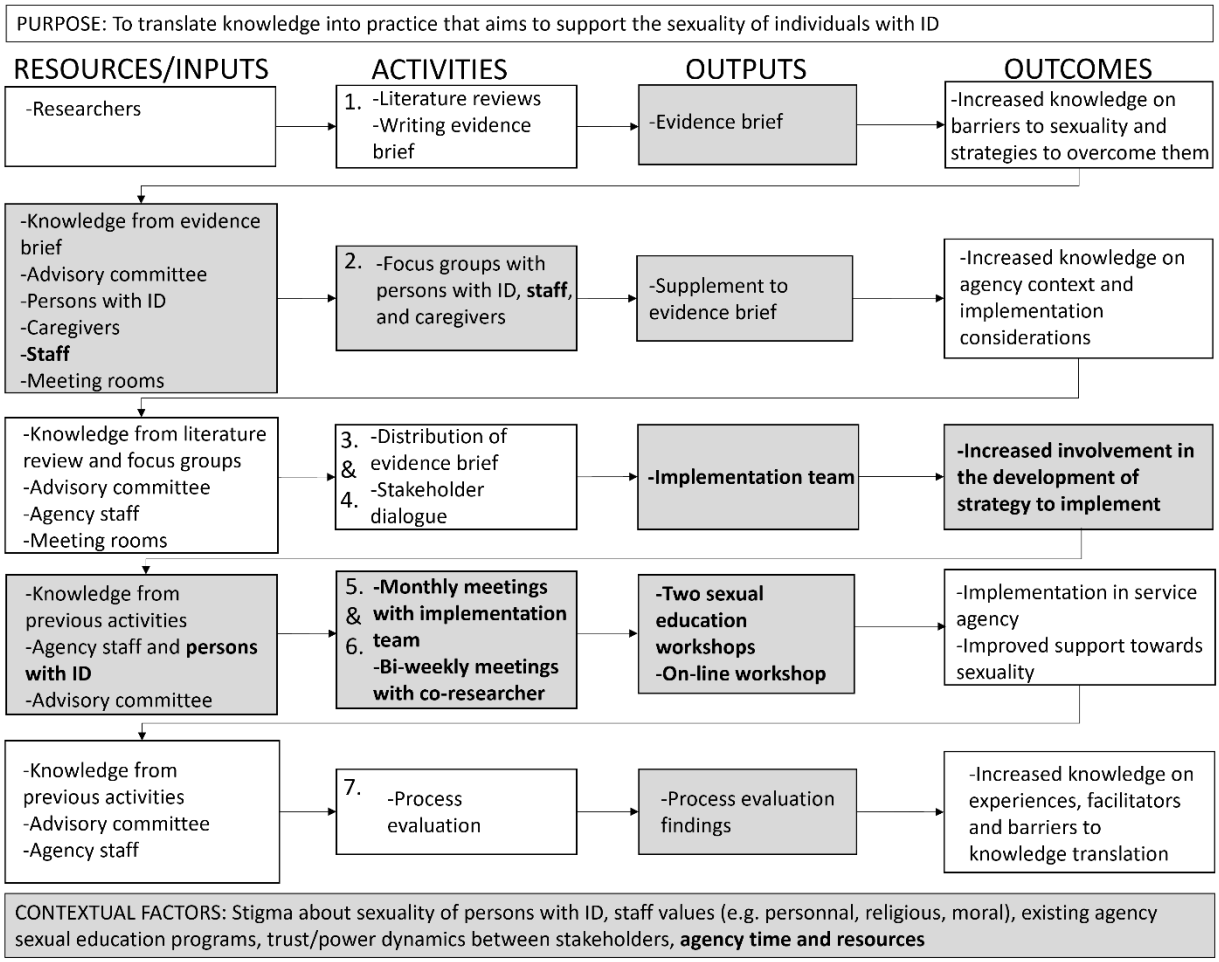
Participants' Experiences. Qualitative data on the participant's experiences collected through discussions and self-report questionnaires were analyzed using thematic analysis, comparable to the one described above under Feasibility of the Intervention.

Findings

For ease of reporting, we separated process evaluation findings into two distinct subsections. First, we highlight key similarities and deviations between the intended logic model for the IKT intervention and the actual study activities. Findings are presented according to the study's steps. Second, we present the thematic analysis findings that explore the facilitators and barriers to IKT intervention in greater depth.

Intended Versus Actual Process

At the end of the IKT intervention, the primary researcher developed a logic model of the intervention as delivered (Figure 2.1). This actual logic model was compared to the intended model (Figure 4.1) to determine how and if activities were delivered as planned. The following subsection presents the findings from the comparison between the models for each study step.



Note. Grey boxes and bolded text represent changes from the intended logic model (Figure 2.1).

Figure 4.1 Logic model describing the actual integrated knowledge translation intervention

1. **Development of a Proposal for Change.** A scoping review intended to identify two to three strategies to support the sexuality of persons with ID; however, a total of five strategies from three articles were identified in this step.

The advisory committee suggested separating participants into two distinct groups as adults with ID receive different services from the agency. For the first group, receiving residential services, the advisory committee members described persons with ID as having high support needs, basic sexual knowledge, and an individual sexuality (i.e., non-relational, mainly engaging in masturbation). They identified the second group, receiving support in the community such as employment and leisure supports, having few support needs, being knowledgeable about sexuality, and having a relational sexuality (i.e., in various degrees of partnerships beyond friendship engaging in diverse sexual practices). This split into two distinct groups informed the search strategy of the scoping review. The primary researcher modified the search strategy to include additional terms such as intimacy, sexual relationships, and sexual identity. As expected, the scoping review informed the evidence brief development, the level of evidence, and potential implementation considerations.

2. **Analysis of Actual Performance.** In the actual logic model, front-line staff were added as focus group participants. The advisory committee suggested adding front-line staff to provide a different perspective on the agency's current services, the choice of strategies to implement, and implementation considerations.

Discussions with the advisory committee also informed the following changes. First, advisory committee members distributed invitation letters and consent forms to different services. Front-line staff supporting adults with ID interested in participating provided the

necessary documentation and presented the study objectives. Advisory committee members organized all focus groups from selecting participants, transportation, and staff relief in residential settings. The primary researcher had no interaction with potential participants before study activities.

Second, the focus group procedures varied across groups. The advisory committee suggested reducing the length and scope of focus groups for persons with ID. They agreed that three sets of focus groups for persons with ID lasting 45 minutes each maximized participant focus and minimized cognitive burden. The same participants were expected to partake in all three sessions; however, some were added, and others stopped participating in the additional sessions.

Finally, we conducted additional focus groups for each stakeholder (adults with ID, front-line staff, and caregivers) to reflect the split in support needs of persons with ID receiving services within the agency. There were two distinct focus groups (group A and group B) for each stakeholder, for a total of 10 focus groups (see Table 4.1). The increase in the number of focus groups led to a greater diversity of the voices represented by providing the primary researcher with an opportunity to make discussions accessible to individuals with varying support needs, as well as an opportunity to include discussion points most relevant to focus group participants.

3 & 4- Problem Analysis, and Development and Selection of Strategies to Change Practices. As intended, the advisory committee received the evidence brief to distribute two weeks before a half-day face-to-face stakeholder dialogue.

Upon starting the stakeholder dialogue, only the advisory committee members participating in the dialogue had received and read the evidence brief. The structure of the

dialogue also changed to accommodate senior management. Senior management, one caregiver and one person with ID only participated in the first hour of the dialogue. Front-line staff and supervisors participated in the remaining discussions about strategies in the evidence brief and implementing change. In addition to changes to the structure, the primary researcher did not facilitate the dialogue. A senior researcher moderated the dialogue, ensured that all stakeholders contributed to the decision process, constructively challenged viewpoints using information from the evidence brief, and kept the discussion focused on the task at hand. The primary researcher's task in the dialogue was to provide research evidence such as focus group findings to support discussions and help with stakeholder indecisiveness in choosing interventions of various levels of evidence.

Finally, the stakeholder dialogue did not lead to the intended outcomes. There was no chosen strategy or established implementation plan. Instead, the stakeholder dialogue led to developing an implementation team consisting of advisory committee members, one supervisor and front-line staff from employment services, and one front-line staff from residential services.

5 & 6- Development and Implementation of Strategy. The implementation team was intended to consist solely of agency staff. In this step, it was also expected that the implementation team would implement the chosen strategy within two to four months.

Interestingly, in the first implementation team meeting, members suggested adding two persons with ID. Unlike the intended implementation plan, the primary researcher led the implementation team meetings and implemented the strategy. The implementation team chose to have two sexual education workshops created and implemented by the primary researcher on crucial topics emerging from the focus groups. Interestingly, the implementation team suggested

involving a person with ID in the delivery of the workshops. The research team hired a person with ID receiving support from the agency to modify content and co-facilitate the workshops. The development and implementation of the workshops took longer than intended. The primary researcher developed the content for both workshops in two months. The following two months were spent with the co-facilitator to modify the content and practice delivering the workshops. In the last month, both workshops were delivered on the same weekday, one week apart. Finally, the primary researcher intended to present the workshop to the same persons; however, attendees differed from a workshop to another.

Thematic Analysis of the Facilitators and Barriers to IKT

For this subsection, we present thematic analysis findings on the facilitators and barriers to IKT identified throughout the IKT intervention. Through participant's experiences, we explore in further detail why the intended logic model was altered and the influences these changes may have on the implementation of the intervention.

The main themes depict the influence of the target group and the setting. Themes and categories within each theme are defined in the following subsection and in Table 4.2.

Table 4.2 *Classification of themes and categories from the thematic analysis*

Themes	Categories	Definition
Influence of the target group		Influence of those benefiting from the implementation of change.
	Involvement of persons with ID in IKT intervention	Degree in which persons with ID were included throughout the IKT process.
	Power dynamics	Influence of perceived power differences on how persons with ID engage and interact throughout the IKT process.
	Accessibility requirements	Implementation considerations related to the accessibility of the intervention
Influence of the setting		Influence of the setting in which IKT is occurring.
	Funding and financial resources	Financial resources available to support the IKT intervention.
	Stakeholder engagement	Degree to which various stakeholders were engaged in the IKT process.

Influence of the Target Group. The IKT intervention was greatly influenced by the target benefiting from implementation: persons with ID (i.e., adults with ID currently receiving services within the agency). This subsection begins with the degree of involvement of persons with ID in the IKT intervention.

Involvement of Persons with ID in the IKT Intervention. Persons with ID were involved in the IKT process to various degrees. They, directly and indirectly, influenced decision-making and the development and delivery of the sexual education workshops.

Persons with ID mentioned the benefits of being included in the IKT process. In focus group B, one person with ID reported that peer education provides credibility, shared experience, familiarity and inspires confidence to overcome trauma.

> *« Je pense que ça montre qu'ils ne sont pas tout seuls. Quand tu as une déficience intellectuelle, tu vis des traumatismes, tu vis des choses que comme d'autres personnes ne vivent pas. Au moins, la personne, ils vont voir que comme elle a une déficience intellectuelle, moi je peux aussi changer des choses dans moi. Ça donne un peu de confiance. (…) Juste faire un sourire, puis connaître les noms (…), ça leur fait aussi sentir comme je veux être ici parce que je connais la personne. »*

Furthermore, multiple participants in focus group B expressed a desire to facilitate a sexual education program. One person with ID asked if it would be a volunteer or paid position, and if a resume was required to apply. *« Mais est-ce que ça serait plus comme bénévole ou genre elle serait payée, ça prend-tu un résumé, ça prend – qu`est-ce que ça prendrait pour – Moi, je suis comme vraiment intéressée »*.

From the service agency's perspective, it is part of their mission to have persons with ID at the forefront when making decisions. Staff highlighted that information from focus groups with persons with ID should inform decision-making: *« Mais on devrait choisir selon ce que les personnes veulent »*. During the stakeholder dialogue, one front-line staff member mentioned wishing persons with ID were present to share their ideas: *« J'aurais aimé que les personnes soient là pour donner leurs idées »*. This dialogue ended with the creation of the implementation team, which included two persons with ID. In the implementation team meetings, staff would directly ask participating persons with ID their preferences towards strategies for

implementation. Previous or current information received from persons with ID ultimately informed implementation decisions.

Interestingly, the degree of participation of persons with ID in the IKT process was subject to debate. Although agency personnel want to include persons with ID further, they reported a concern that persons with ID may not have the capacity to participate in high-level discussions. A supervisor commented that without including persons with ID more often, they could not be expected to understand the context of these discussions:

> *« À la base, comment peut-on s'attendre à ce que (personne ayant une DI) ait une idée de quoi on parle quand on lui en a jamais parlé (…) Si elle avait été invitée à plusieurs rencontres, à un moment donné elle aurait capté quelque chose. »*

When consensus could not be reached on whether to include persons with ID in potential sexual education workshops for staff, a supervisor noted some resistance to inclusion: *« Je trouve ça super intéressant, puis c'est juste la résistance que je vois. Même, plus dans nos valeurs, c'est d'inclure les personnes dans ces formations-là. Je vois une résistance déjà »*. In response to this debate, one person with ID mentioned how great it was that persons with ID were included in this debate and not being othered. Furthermore, agency personnel and persons with ID should participate in the same workshop, given their similarities and the benefits of having shared experiences.

> *« Je pense que c'est vraiment bon qu'on parle comme ça. Oubliez pas qu'on ne parle pas de vous autres mais de NOUS autres. (…) Regardez, vous faites la même chose que nous autres. C'est ça qu'on a besoin d'entendre des fois. Parce que des fois, avec une DI ou différent, on pense qu'on n'est pas pareil, mais on est pareil. »*

The implementation team eventually agreed that having persons with ID sharing their lived experiences in the workshops could be beneficial. *« Je vois que (personne ayant une DI) aimerait ça donc qu'on lui donne la chance de faire des diapos par rapport à ses témoignages et qu'elle puisse verbaliser... et elle pourrait aller tant pour les employés ou les personnes »*. This led the research team to hire a person with ID for a three-month contract to collaborate with the primary researcher in developing and facilitating the two sexual education workshops.

In a post-study interview, the co-researcher involved in the development and facilitation of the sexual education workshops expressed the importance for researchers to be working with persons with ID. *« Je pense que c'est important pour (chercheure) d'apprendre ce qu'est de travailler auprès d'une personne ayant une déficience intellectuelle. Je pense que c'est important d'exposer les gens aux gens ayant une déficience intellectuelle »*. The co-researcher was grateful for the experience and believed the study will help them grow and further develop acquired skills.

The primary researcher also noted benefits to including a person with ID in delivering the workshops, such as familiarity and openness with participants, which was not present during the focus groups.

> *« J'ai fait des groupes de discussion avec eux et j'ai vu l'interaction. C'est différent une fois que (co-chercheure) est là. Ils se sentent cent fois plus à l'aise. Dans les groupes de discussion, j'ai eu de la misère avec les gens de commencer à parler de sexualité. »*

The primary researcher also mentioned increased experience sharing and credibility through the involvement of the co-researcher.

> *« (Co-chercheure) connaît les membres de (l'agence de service), donc déjà il y a un partage d'expériences que moi je ne pourrais pas faire. (Co-chercheure) est une adulte ayant une déficience intellectuelle donc en termes de ses expériences, même si elle ne connaît pas les personnes qui étaient dans la pièce, c'était plus [crédible]. »*

Finally, the co-researcher helped the primary researcher realize that content needs to be presented slowly and clearly. The primary researcher assumed their presentation was clear because of how familiar the content became throughout the process.

> *« Je trouvais que l'exemple qu'elle avait, la façon qu'elle parlait, ça m'a fait réaliser que je dois vraiment changer la façon que j'interagis avec ces personnes. Je parle vite, je ne parle pas très fort et je tiens pour acquis que ce que je présente est clair. Je suis tellement dans mon domaine que je ne le réalise pas nécessairement. Donc (co-chercheure) m'a aidé à comprendre comment sortir de ça. »*

Power Dynamics. This category refers to an imbalance in power exerted by various stakeholders throughout the IKT intervention. Despite a representation of all parties affected by the issue around supporting the sexuality of persons with ID, study participants were not on equal grounds throughout the study.

The primary researcher had a dual role throughout the study. First, the researcher had an active role as a subject matter expert by sharing knowledge from previous study steps. Second, the researcher had a passive role as a participant in the IKT intervention and was influenced by participants' interactions. For example, in the workshops' development, the primary researcher provided additional information to the co-researcher to justify decisions made on the content and the delivery. It was impossible to establish if decisions were made as equal participants involved

in the decision-making or if the co-researcher agreed with what was proposed by the primary researcher, a subject matter expert:

> *« Est-ce que je connais (co-chercheure) ? Pas tant que ça, non plus. Je ne sais pas comment elle est avec les autres. C'est difficile de savoir si ça vient d'elle parce qu'elle le voulait ou si c'est moi, sans le savoir, qui lui donnait une pression. »* (Primary researcher, post-study interview)

Furthermore, the primary researcher directly influenced whether the co-researcher would continue in the study. The co-researcher expressed discomfort with facilitating large amounts of content and asked to be removed from the study. Through discussion, the co-facilitator expressed a desire to continue if the research team significantly reduced their contribution to presenting workshop activities and real-life experiences: *« En travaillant collectivement ensemble, j'ai pu trouver des solutions au problème ou au défi qui s'est présenté à ce moment-là »*.

Front-line staff who participated in the sexual education workshops also had a dual role. They were recruited to learn aside persons with ID; however, some supported participating persons with ID in the workshop activities. The roles of the staff were different from one workshop to the next. In the first session, the front-line staff would not answer any of the facilitators' questions. Instead, they would encourage persons with ID to answer by providing lived examples or encouragement. As the workshop progressed and knowledge new to front-line staff was presented (such as different sex toys), front-line staff became learners. In the second workshop, staff exclusively supported persons with ID in answering questions, participating in activities, and filling out the workshop evaluation questionnaire. The primary researcher noted difficulties establishing what role staff had, whether it was as learners or as support staff,

especially in the second workshop, where participants' support needs appeared higher than in the first.

> *« C'est difficile parce que dans la deuxième (formation), je trouvais que la ligne n'était pas aussi évidente… quel staff était là pour être [apprenant] et quel staff était là pour offrir du soutien. Ce n'était pas clair parce que les niveaux de soutien étaient différents que dans la première (formation). »*

Accessibility Requirements. This category is on reducing barriers to the IKT process so that all relevant stakeholders may benefit from the knowledge translated in this study.

Multiple implementation considerations were around the accessibility of the chosen strategy for persons with ID. Front-line staff believed that if a person with ID facilitated the strategy's implementation, the knowledge shared would be more applicable and accessible to persons with ID:

> *« Si c'est la personne (personne ayant une DI), au niveau du langage, cela serait déjà adapté. C'est déjà un plus. Parfois c'est difficile pour nous de parler – parce que lui (personne ayant une DI) a déjà suivi la formation. On lui a expliqué, puis il a vu ça dans ses mots à lui, dans son langage, qui est le même langage que ses pairs. »*

In preparing the workshops, the co-researcher guided the primary researcher to make the content and activities more accessible to persons with ID. This involved going over the entire content prepared by the primary researcher, slide by slide as it was in PowerPoint format, to check the vocabulary and modify content.

> *« C'était vraiment juste repasser à travers le contenu et de donner mes avis et mes opinions. Voir ce qui fait du sens, qu'est-ce qui ne fait pas de sens, est-ce que ça c'est un trop gros mot à utiliser là. Est-ce qu'on devrait mettre ce paragraphe-là plus tôt dans cette présentation-là. Avec (chercheure), j'ai donné beaucoup de mon avis pour qu'on puisse faire en sorte que le projet soit simplifié pour les personnes ayant une déficience intellectuelle. »*

Although the co-researcher's involvement increased accessibility of the content, the short time frame to practice facilitating the workshops was not accessible to persons with ID. In a couple of months, the co-researcher had to memorize content for two separate workshops given one week apart. This time constraint may have led to increased pressure on the co-facilitator to memorize unfamiliar and sensitive content. The primary researcher noted in a post-study interview that although it was feasible to learn to facilitate two separate workshops in a limited time, it was not ideal for the co-researcher. It would have been more accessible to practice only one workshop at a time.

> *« On aurait pu le faire mais pas d'avoir deux formations. Là, on demande à une personne ayant une déficience intellectuelle de mémoriser deux choses qui sont sur le même thème, de mémoriser deux choses en même temps, parce que la formation était une semaine après l'autre. »*

The co-researcher noted some challenges with information retention when practicing the workshops, such as mixing up the content from one workshop to another:

> *« Je me rappelle qu'il y avait eu quelques défis par rapport à la mémorisation du contenu (…) On a dû beaucoup changer le contenu pour que ça devienne plus clair et plus*

> *compréhensible pour les gens, comme moi, ayant une déficience intellectuelle. Lorsque je lisais les papiers, des fois je sautais une ligne ou je pensais que je devais dire ça mais ça c'était pour une autre présentation. »*

Eventually, the co-facilitator felt stressed and asked to speak with the research team to modify their participation in the workshops.

> *« Pour une des présentations, je me souviens, il y avait une situation où je ne me sentais vraiment pas à l'aise parce que j'ai trouvé ça beaucoup trop de contenu pour moi. Donc, j'ai demandé à (chercheure) qu'elle reprenne un bout de sa présentation pour que ça m'en enlève un peu à moi. »*

At the end of the workshops, multiple participants reported that their favourite part was visual aids. For example, workshop attendees enjoyed the use of physical examples of sex toys: *« J'ai bien aimé quand ils ont montré les jouets car je ne les connaissais pas tous »*. The primary researcher noted that despite the first impression of discomfort, participants enjoyed handling the various sex toys: « *J'ai présenté des jouets sexuels et les gens ont pu les toucher, rire et parler. Je trouvais que oui, c'était un choc mais les gens ont bien réagi* ». Another participant appreciated the physical models to show the different methods of contraception. The use of animations to show the process of ovulation and ejaculation was also well-received: *« Animation ovule et sperme = EXCELLENT! »*. In the post-study interview, the primary researcher noted that participants seemed to pay more attention when the co-researcher was presenting. This was perhaps due to the increased credibility of a person with ID or because they spoke more slowly and explained examples in detail, whereas the primary researcher tended to provide quick examples that were not necessarily accessible to persons with ID.

> *« Je pense que le staff et les personnes recevant les services écoutaient possiblement plus (co-chercheure) à cause de ça (crédibilité), mais aussi dans sa façon de présenter le contenu. Elle parlait plus lentement, elle expliquait ses exemples. (…) J'avais plus tendance à faire un exemple rapide, genre une phrase, mais qui n'est pas nécessairement accessible pour une personne ayant une déficience intellectuelle. »*

In areas of improvement, participants mentioned using additional visual aids, adding activities such as colouring or requiring physical movements, using a simplified vocabulary, and speaking more slowly.

Influence of the Setting. The setting in which the IKT intervention occurred may have influenced the translation of research evidence. In this study, the IKT intervention was influenced by the available funding and stakeholder engagement.

Funding and Financial Resources. Available financial resources determined the service agency's participation in the study.

Front-line staff participating in study activities during working hours, regardless of the study activity's length, would have to be paid for four hours of work. One supervisor in the stakeholder dialogue noted that participants would have to volunteer to participate outside of work hours: *« S'ils venaient, il faudrait les mettre bénévoles, volontaires, pas rémunérés. Une formation de deux heures serait rémunérée quatre heures. On ne peut pas ouvrir cette porte-là »*. Furthermore, financial restrictions influenced the choice of strategy. Strategies such as existing sexual education programs typically require payment to follow courses. One front-line staff explained in a focus group that these were not feasible for persons with ID as they have limited finances and require grants to participate:

> *« Le côté financier est un très gros problème. Il faut une augmentation pour leur aider. Il y en a qui n'ont pas assez pour se nourrir. Combien est-ce que la personne va payer pour le cours? S'ils veulent que les gens puissent chercher l'information ailleurs, il faudrait qu'ils aient les subventions nécessaires pour aller prendre un cours. »*

When discussing the chosen strategy to implement, implementation team members had concerns over the capacity of the agency to support long-term or continuous implementation, especially as external resources had to be paid. For this reason, many discussions were around the possibility of training agency personnel to replace the primary researcher:

> *« Je pense de regarder comment le faire et où le faire. Est-ce un employé- parce qu'on va dire que c'est toi (chercheure) qui va venir, il n'y a rien au côté des sous, voir le budget. Qui va te remplacer? C'est-tu une personne en particulier qui est formée? »* (Front-line staff)

Stakeholder Engagement. It was challenging to maintain stakeholders' commitment to study activities given that the IKT intervention lasted over two years and involved many repeating participants.

Regarding logistics related to planning and executing the various study steps, the IKT intervention also required high effort from the advisory committee. All documentation, such as the distribution of invitation letters, consent forms and the evidence brief, were managed by the advisory committee. In addition to the documentation load, one implementation team member reported that persons with ID might require frequent reminders before and transportation to and from study activities: *« Beaucoup de logistiques. Il faut leur parler une semaine avant et les rappeler »*. Participating front-line staff who support persons with ID not participating in the

study also had to be replaced. Given the study's scope and length, these tasks were demanding, which led one advisory committee member to leave the project after the first set of focus groups for persons with ID.

The following study steps were not coordinated as clearly. For example, the stakeholder dialogue structure was modified to accommodate senior management, who could only attend the first hour due to competing priorities. Their role in the dialogue was not to inform decision-making, but rather to gather information on previous study steps and show their support towards the intervention. This meant that decisions around the strategy's choice and potential implementation considerations were made without senior management. Interestingly, the representation of caregivers and persons with ID in the stakeholder dialogue who participated in the focus groups was low (one caregiver and one person with ID).

Furthermore, participation in the questionnaires was low for the stakeholder dialogue. Only three agency personnel, members of the advisory committee, received the evidence brief and completed the questionnaire on the evidence brief's content. They reported a slight agreement that the evidence brief content was clear (scores ranging from 2 to 5, M= 3.67), did not agree nor disagree that the evidence brief provided new information (scores ranging from 2 to 4, M= 3.33), and all agreed that the evidence brief informed discussions during the stakeholder dialogue (M= 4). With the addition of one caregiver, these participants also completed the questionnaire on the stakeholder dialogue structure; however, one advisory committee member left the remaining fields blank. Respondents reported agreement towards a fair distribution of various stakeholders during the discussion (score ranging from 3 to 5, M= 4). They strongly agreed that they had the opportunity to share their opinions (M= 5) and that their opinions were discussed and considered (M= 5). Two respondents agreed that disagreements were resolved during the discussion (M=

4.5), whereas one respondent reported no disagreement. Finally, all respondents strongly agreed that the dialogue met its objectives and helped discuss strategies of varying levels of evidence and critical implementation considerations (*M*= 5).

There were some misunderstandings from the implementation team around participation in the workshops. We expected the same participants to attend both sexual education workshops as the second workshop built on concepts from the first workshop. Furthermore, the second workshop participants had higher support levels and would have been more suited for the first. The staff did not understand why they were not invited to the first workshop and asked for clarification: *« Il y a beaucoup de liens que vous avez fait entre la formation d'aujourd'hui et la formation de la semaine dernière. Mais c'est que, il y en a parmi nous qui n'étaient pas là »*. All participants in the sexual education workshops completed the self-administered questionnaire (see Table 3.5). Participants generally agreed that the workshop's content and activities were clear and appropriate (means ranging from 4.23 to 5). In the second workshop, the co-facilitator also completed a questionnaire. Scores were generally lower in this workshop; however, participants agreed that the workshop's content and activities were clear and appropriate (scores ranging from 3.64 to 4.45). Areas for improvement indicated by respondents were in the workshop's interactive parts, such as the activities.

The study's duration also influenced the primary researcher's engagement in developing and implementing the sexual education workshops. The primary researcher had to develop five hours of content for two sexual education workshops within two months. The following two months were used to adapt the content and support a person with ID co-facilitating the workshops. The primary researcher expressed concerns in the post-study interview over the limited time allotted for this step and the impact on the quality of the workshops:

« C'était un long projet. (…) [J]'ai développé le contenu [des formations] en deux mois. Ce n'est pas beaucoup de temps pour [créer] un programme d'éducation sexuelle. »

Discussion

The objective of this chapter was to determine barriers and facilitators to an IKT intervention within a community-based service agency providing services to adults with ID. The intervention did follow the main intended study activities, although some changes were made to tailor the intervention to the setting. We also identified facilitators and barriers to the IKT intervention that we will discuss below under the themes power dynamics and accessibility of the intervention.

Power Dynamics

Knowledge translation is traditionally led by the research team. Knowledge users are involved later in the process as consultants to help with knowledge dissemination. IKT marks a shift and demands that all stakeholders have equal grounds to contribute their knowledge and expertise. In the current study, we have applied the principles of IKT. Its evaluation reveals challenges and facilitators to the inclusion of stakeholders in the IKT intervention.

In this project, IKT was chosen over other collaborative approaches for knowledge translation for the direct involvement of decision-makers in the IKT process. By having senior management's support, it was possible to address challenges with recruitment, the sensitivity of the topic, and implementation. As per an expert on IKT from the study by Nguyen et al. (2020): "Decision makers who are partners have some kind of power to help implement the findings (chosen specially because of their position/power not because they are disempowered)". This means that although there were power imbalances, agency personnel facilitated the IKT

intervention. It would not have been possible to engage in an IKT intervention of this scope without the agency's support. Furthermore, it was essential to have pre-determined steps and objectives for the IKT intervention approved by agency personnel. By doing so, the primary researcher ensured the feasibility of the intervention as part of a Ph.D. The project also had to lead to implementation to avoid disappointing project participants (Herr & Anderson, 2005) who agreed to participate based on expected outcomes.

The influence of agency personnel also facilitated opportunities for persons with ID to engage in the IKT process. Much like previous research, persons with ID in this study relied on support from staff to participate in study activities (Howell & Shogren, 2019; McDonald, 2012). For example, members of the advisory committee ensured documentation such as invitation letters and consent forms were given to persons with ID and organized transportation to and from study activities.

The involvement of agency personnel may have also restricted opportunities for persons with ID. In this study, participation was limited to those chosen by the advisory committee, consisting of different service supervisors and one front-line staff. The primary researcher could not approach potential participants directly (e.g., persons with ID residing in various locations). It is not clear how the service agency chose specific participants if the study information was sent to all persons with ID and if those who wanted to participate were given a choice. This control over recruitment may undermine the autonomy of persons with ID by denying them the right to hear about the study and choose to be included (Lennox et al., 2005; O'Brien et al., 2014). However, it is likely that the service agency did not intend to undermine the autonomy of persons with ID in the IKT intervention. Agency personnel are in a challenging position where

they must balance the legal obligation to protect persons with ID from potential harm and respect their rights to inclusion.

Accessibility of the Intervention

Whether persons with ID could participate in the IKT intervention relied on the accessibility of the process itself. Specifically, the inclusiveness of research activities and outputs. In this project, several measures were put in place to increase the accessibility of the IKT intervention.

One challenge in research with persons with ID is that those with high levels of support, identified in some articles as moderate to severe ID, are often excluded from research (Feldman et al., 2014; Gibbs et al., 2008). By excluding those with higher support needs, they are denied opportunities to share their lived experiences and preferences. For research outputs and outcomes to be relevant, it is important to include persons with ID with high supports needs (Aman & Handen, 2006; McDonald et al., 2013; McVilly & Dalton, 2006). We adapted focus groups methods to increase the accessibility of this step of the intervention to persons with ID with higher support needs. Focus groups enable the participation of persons with ID of varying support needs (Feldman et al., 2014; Gibbs et al., 2008) and provide a safe environment to share their experiences (Tassé et al., 2005). However, it became clear through discussions with the advisory committee that it would not be possible to conduct focus groups with persons with ID without considering support needs. By dividing persons with ID into two distinct groups per service received, the focus groups became more accessible. For example, participants in each group had previous interactions and shared experiences. This allowed participants to support each other with memory recall or by finding examples to add to the knowledge shared by participants. It was possible to identify knowledge and leverage expertise specific to each group,

increasing the relevance and use of the final research outputs: the two sexual education workshops and the online program.

Accessibility of the IKT intervention increased through the involvement of persons with ID. For example, the sexual education workshop content was greatly influenced by the co-researcher. The content was simplified using plain language, limited use of text and additional images, all strategies known to increase the accessibility of research outputs (Hale et al., 2011; Kuijken et al., 2016; Sandjojo et al., 2019). Additionally, the workshop delivery became more accessible for persons with ID; the co-researcher presented more slowly and gave examples that participants could more closely relate to compared to those provided by the primary researcher. This is consistent with findings from a previous study with co-researchers with ID (O'Brien et al., 2014). In this study, co-researchers with ID ensured reported findings were accessible, concise, and represented how persons with ID saw their lives (O'Brien et al., 2014).

We did face some challenges in involving the co-researcher. The involvement of the co-researcher in this project required additional time and effort. Previous research has shown that research involving persons with ID requires additional time and resources for preparation and practice (repeating and revising) compared to researchers without ID (O'Brien et al., 2014); and for effective communication and collaboration (Garbutt et al., 2010; Palmer & Paterson, 2013). To increase accessibility, additional time should be considered when developing the IKT intervention plan. For example, additional time to train the co-researcher in facilitating the sexual education workshops may have led to greater involvement in the delivery of the workshops.

It was challenging to involve persons with ID at the beginning of the research process. The project was conducted in the context of a Ph.D. in which research objectives and methods

had to be established before engaging with persons with ID. A previous study exploring how to engage in participatory research with persons with ID met the same challenge (Dorozenko et al., 2016). In response, researchers must find ways to create opportunities for persons with ID to make decisions and exert control throughout the research process (Dorozenko et al., 2016). One way to support persons with ID in engaging in the research process is to increase their understanding of research processes and skills to meaningfully engage in research by providing research training programs (Fullana Noell et al., 2020). However, findings from this chapter also reveal that simply by engaging in research, persons with ID gain confidence, skills, and research interests. The co-researcher from our project continued as an advisory committee member on other projects led by the research team.

Finally, using collaborative methods such as IKT increases the accessibility of the research activities and outputs. By engaging in reflexivity, the process of reflecting on knowledge production and creation (Guillemin & Gillam, 2004), researchers may identify strategies to improve accessibility throughout the study (Dorozenko et al., 2016; Guillemin & Gillam, 2004). Through the iterative nature of IKT, researchers can then modify the research process accordingly. For example, in this project, we planned to conduct a single one-hour focus group with persons with ID, per level of support, to discuss existing services, areas for improvement and implementation considerations. Upon consultations with the advisory committee, we understood that this was too demanding and complex for a one-hour session. Focus groups with persons with ID were separated into three separate sessions, each on a different topic. This reduced the cognitive burden by focusing on one topic per discussion. This project highlights the importance of using collaborative approaches to support the meaningful participation of persons with ID in research.

Limitations

Given the reduced distribution of the evidence brief, only a small sample of self-reported questionnaires was completed and received by the primary researcher following the stakeholder dialogue. There is little evidence to inform the relevance of using an evidence brief and the stakeholder dialogue to support discussions on supporting the sexuality of persons with ID. This low response rate may be explained by a misunderstanding of the expectations of the primary researcher, which could be addressed by creating clear roles and responsibilities for the advisory committee. Furthermore, additional time could be allotted for senior management to complete the questionnaire during the dialogue, addressing issues around competing priorities.

Another limitation is in the transferability of the findings. Only one service agency participated in the study. The participating service agency was francophone, a population with a specific socio-demographic profile. The agency operates in the context of a linguistic minority, meaning that findings may not apply to anglophone service agencies in the same area. Additional research is required to understand the impact of language on knowledge translation, primarily when research evidence is mainly generated and disseminated in English.

Conclusion

Using collaborative approaches to knowledge translation, such as IKT, increases the accessibility and relevance of research for persons with ID. These methods also provide opportunities for persons with ID to share their voice which has long been excluded from research. It is essential to continue using collaborative methods when doing research with persons with ID. Additionally, by analyzing the underlying processes of knowledge translation, researchers gain a better understanding of how to increase the accessibility of interventions which may further reduce the know-do gap.

Chapter 5 – General Discussion

In this final chapter, we present the general discussion of the dissertation where we reflect on the findings of previous chapters.

Overview of Dissertation

This dissertation sought to engage in and evaluate an integrated knowledge translation intervention to support the sexuality of persons with ID in a community-based service agency. Additional support towards the sexuality of persons with ID is of the utmost importance to promote the sexual autonomy and increase the sexual knowledge of persons with ID. The project aimed to understand the process that facilitates or hinders how stakeholders collaborate to create, share, and use the knowledge on supporting the sexuality of persons with ID in a community-based setting.

Chapter 1 provided an overview of the project, the study context, and the objectives of the dissertation. We also provided general background information on the need for support towards the sexuality of persons with ID and conceptual models for knowledge translation. This chapter emphasized the importance of the evaluation of knowledge translation processes in the community sector. Chapter 2 outlined the research methods used throughout the project. In Chapter 3, we conducted a scoping review to identify the best and promising practices supporting the sexuality of persons with ID. We consulted and collaborated with various stakeholders to identify, develop, and implement a strategy to support the sexuality of persons with ID at the target service agency. The primary researcher used pre-structured case summaries to identify relevant knowledge from different stakeholder groups, including preferences and considerations for a strategy implementation within the target service agency. The primary output of this IKT intervention was two sexual education workshops on sexual health and practices for persons with ID and front-line staff. In Chapter 4, the evaluation of the IKT process, we used a thematic analysis to identify facilitators and barriers to conducting an IKT intervention on supporting the sexuality of persons with ID in a community-based service agency. Data

analysis revealed two main themes, each with subthemes. The main themes included the influence of the targets who will benefit from the knowledge translated and the influence of the setting in which knowledge is being translated.

In this chapter, we expand on findings from previous chapters. Specifically, we discuss knowledge gained from the primary researcher's experience and from identified barriers and facilitators to IKT within a community setting. One recurring theme throughout the project was the participation of adults with ID and whether the IKT process is accessible to them. In this chapter, we will discuss different ways to address issues around the paucity of evidence, the need to adapt knowledge translation models and frameworks for the community setting, and the multiple roles that researchers have in conducting IKT interventions. This chapter concludes with the dissertation limitations and implications of this study for future research and practice.

The Paucity of Evidence

Knowledge translation models and frameworks developed for clinical settings rely on the assumption that high-quality evidence is available and relevant. This is particularly challenging in an understudied field, such as intellectual disability. It is also possible that knowledge in this field is too novel to warrant the use of high-quality research methods such as randomized-control trials or long-term follow-ups. Additionally, the process of generating this type of evidence is resource and time-intensive (Hariton & Locascio, 2018). Research in the context of Covid-19 has shown the benefits of expediting the process to meet the immediate needs of the population (Lipworth et al., 2020). In community-based settings, there could be benefits in immediately addressing the needs of those receiving services while waiting to develop and implement high-quality evidence. This may be particularly important for persons with ID whose sexual rights have

been historically contested, and consequently, continue to experience barriers to a meaningful sexuality (e.g., high rates of sexual abuse, low sexual knowledge, limited opportunities to form meaningful sexual relationships).

The accessibility of research for both researchers and those being studied is also tied to policy development and priorities. Until recently, diversity and inclusion were not government priorities in Canada. For example, in 2018, the Tri-Agency released a statement on equity, diversity and inclusion highlighting their commitment to "identifying and eliminating obstacles and inequities in the research ecosystem to support equitable access to funding opportunities, embed [Equity, Disability and Inclusion]-related considerations in research design and practices, and increase equitable and inclusive participation" (Government of Canada, 2021b). This initiative aims to increase the number of researchers from underrepresented groups (e.g., Indigenous peoples, persons with disabilities and visible minorities) and favour inclusive research practices. Furthermore, the Race, Gender and Diversity Initiative (2021) will be launched by the Social Science and Humanities Research Council (Social Sciences and Humanities Research Council, 2021). This initiative aims to support community-based and -led research partnering with postsecondary institutions that target underrepresented and disadvantaged groups, including persons with disabilities and focuses on the co-creation of knowledge on critical issues related to equity in Canada. With this shift in government priorities, more funding is available to disability researchers, inclusive research designs and practices are promoted, and community-based organizations are supported to participate in research (Government of Canada, 2021a; Social Sciences and Humanities Research Council, 2021). This shift may increase the quality and quantity of available evidence in the field of intellectual disability and knowledge translation in community-based

settings. However, community-based organizations may lack the time, resources, and skills to implement this evidence even if it were available.

Need to Adapt Knowledge Translation to the Community Setting

To increase the engagement of community members in the IKT process, IKT models and frameworks need to be adapted to the context of community-based organizations. One important IKT step for community-based organizations consists of increasing awareness of knowledge translation processes, the associated language, and the importance of this type of research (Lal et al., 2015). This is referred to as knowledge translation competency development (Greenhalgh & Russell, 2006; Proctor et al., 2013; Straus et al., 2011). Training initiatives exist to address the need for knowledge translation competency development; however, these tend to target researchers and health care providers (Provvidenza et al., 2020). These curriculum-based initiatives may not be relevant and designed for community members.

Community-based settings may lack the capacity and skills to access scientific articles (Kothari & Armstrong, 2011) and engage in knowledge translation (Elsabbagh et al., 2014). Those working in community-based organizations supporting persons with ID have a socio-demographic profile grounded in practice-based learning with limited research knowledge. For example, the program to train workers supporting persons with ID at a French college in Ottawa does not contain courses initiating them to research (La Cité, 2021). The training of support workers consists of learning practical skills through coursework or on-the-job practicums (Kelly, 2017). As for persons with ID, many experience socioeconomic disadvantages compared to persons without ID. In the *Atlas on Primary Care of Adults with Developmental Disabilities in Ontario*, a study involving over 66,000 adults with ID, more than twice the number of adults with ID lived in the poorest neighbourhoods than in the wealthiest neighbourhoods (19,987 vs.

9,226) (Lunsky et al., 2013). Furthermore, an analysis of the Canadian Survey on Disability (2017) revealed that persons with ID were more than four times more likely to have never completed high school compared to people who did not have a disability (40% vs 9.7%) (Berrigan et al., 2020). These pose significant challenges for persons with ID as research evidence is often published in peer-reviewed journals, which often require payment to access and high literacy levels to understand (Barwick et al., 2008; Dew & Boydell, 2017).

Building knowledge translation competency may facilitate the active participation and collaboration of knowledge users, both key for effective knowledge translation practice. In fact, a previous study has shown that participation in a knowledge translation competency training program in a community-based hospital led to an enhanced appreciation of the importance of KT and positive changes in KT knowledge, skills, and attitudes (Provvidenza et al., 2020). Future research should consider developing competency development training programs for knowledge users with limited exposure to research and who have an ID. This would ensure that training is accessible to all, including community members and those often excluded from research, to further advance effective knowledge translation practices (Greenhalgh & Russell, 2006; Proctor et al., 2013; Straus et al., 2011).

Alternatively, IKT researchers could consider ways to collaborate with community-based organizations that differ from the traditional method of being on-site as required for data collection. It would be interesting to explore an approach where the IKT researcher remains on-site throughout the IKT intervention to address issues around communication of KT activities. Another approach would be to increase collaboration between community-based organizations and research institutions. For example, a university institution in Quebec is affiliated with various research and community partners to build a local and provincial knowledge network on

intellectual disability and autism spectrum disorders (Institut universitaire en déficience intellectuelle et en trouble du spectre de l'autisme, 2021). Community-based organizations may also participate in community-engagement scholarships with researchers which result in "scholarship deriving from teaching, discovery, integration, application or engagement" (Jordan, 2007). The University of Guelph has a Community Engagement Scholarship Institute which provides Community Engaged Teaching and Learning (CETL) programs for both students and community partners to conduct collaborative research as part of undergraduate or graduate courses. This university also supports community organizations to engage in knowledge translation, such as providing guidance on grant applications, hosting events to link researchers with the community, and building capacity through workshops, guest lectures, and communities of practice (Community Engagement Scholarship Institute, 2021). Through these types of partnerships, community-based organizations may gain access to empirical evidence and opportunities to participate in research and ultimately further their understanding of knowledge translation.

Previous research has shown the importance of tailoring interventions to increase their applicability and feasibility (Hale et al., 2011; Young et al., 2012). Guidelines exist outlining the overall steps to effectively tailor evidence; however, these lack sufficient detail for guidelines to be applied (Chen et al., 2013). The involvement of knowledge users is critical to tailor interventions in the community-based setting. For example, the use of technical documents such as evidence briefs, known to be effective in the clinical setting, is not accessible or user-friendly for community members. To increase accessibility, community members should be involved in the development of these materials. Their involvement may also provide a greater sense of ownership (Harrison et al., 2010). Finally, by including and sharing their practical knowledge,

community members are more likely to engage in the knowledge translation process (Kislov et al., 2017).

Challenges in Conducting IKT

Researchers conducting action research, like IKT, may find themselves in ethically sensitive grey areas (Shi, 2006) as they hold various roles. First, they act as gatekeepers of the IKT process by ensuring that projects follow the intended process and lead to expected outcomes (Trondsen & Sandaunet, 2009). To meet the requirements of the graduate program, student researchers may rely on the successful completion of the IKT process. For this reason, they may be lenient with study activities, such as the inclusion criteria to involve participants that are key for the success of the project (Hay-Smith et al., 2016). Second, student researchers may also passively influence the IKT process as participants. As subject-matter experts, they identify the knowledge at the foundation of IKT. They are typically the first to interpret relevant scientific evidence and share their interpretation with relevant stakeholders. In this dissertation, the primary researcher's influence on the IKT process was apparent in the stakeholder dialogue. The primary researcher ensured that implementation discussions would consider the strategies identified in the scoping review. These additional efforts were made to guarantee that project activities would lead to the agreed-upon outputs (Herr & Anderson, 2005) and to meet the requirements of the graduate program.

The multiplicity of the researcher's roles as knowledge providers, knowledge brokers, co-creators and change agents is well documented in process-oriented approaches (Bulten et al., 2021; Wittmayer & Schäpke, 2014). These roles facilitate the IKT process in various ways. In addition to being providers of knowledge, researchers participating in the knowledge creation in IKT interventions gain opportunities to better understand the social and cultural contexts in

which implementation will occur (Trondsen & Sandaunet, 2009). Furthermore, the engagement of researchers in the IKT process supports the iterative, cyclical models of knowledge translation by allowing researchers to identify ways to facilitate and modify an ongoing process (Canadian Institutes of Health Research, 2015; Morrison & Lilford, 2001). In this iterative process, researchers can use the knowledge gained from previous study activities to increase the accessibility of future activities. However, little is known about how researchers navigate these different roles to co-produce knowledge and address conflicts between them. A study by Bulten et al. (2021) found challenges in combining action-oriented roles with knowledge-oriented roles, both key for IKT researchers. They suggest that acknowledging the varying roles that researchers may take in process-oriented approaches, their merit and implications may address challenges (Bulten et al., 2021). Other strategies to support researchers in fulfilling their varying roles include engaging in reflexivity (Bulten et al., 2021) and offering practicums for students to be exposed to collaborative research (Brundiers et al., 2010). Additional research is needed to enhance our understanding of the varying roles of researchers and the impact these may have on the accessibility of IKT interventions.

Limitations

Limitations of the study were addressed in previous chapters. The main limitation was the transferability of the findings. We collected qualitative data from multiple sources (i.e., persons with ID, caregivers, and agency personnel) and used different methods which validated the information provided from different sources. Through this process, we also gained an in-depth understanding of the IKT process, knowledge gaps, and the engagement of stakeholders (Elsabbagh et al., 2014). However, these findings may not apply to a different community-based organization. Nevertheless, by tailoring interventions to the specific needs and context of the

target population, interventions are more readily adopted (Hale et al., 2011; Storey, 2007). Strategies to further engage persons with ID in IKT may still provide helpful insight for other researchers using collaborative research methods.

Implications

Research

This project addresses the paucity of knowledge on methods to conduct IKT in community-based settings by contributing to the understanding of barriers and facilitators to IKT.

First, changes are required in how researchers conceptualize knowledge translation in community-based settings. Existing knowledge translation models and frameworks were developed for the implementation of high-quality evidence in the healthcare setting. However, community-based organizations do not place the same value on scientific evidence when implementing practice change (Kothari & Armstrong, 2011). For this reason, researchers conducting IKT in community-based settings need to reconsider the hierarchy of knowledge (Glasziou et al., 2004), as defined for the healthcare setting, to support the implementation of change. In IKT, researchers' and knowledge users' roles are changed from traditional knowledge translation models to ensure equal collaboration throughout the research process. Traditionally, researchers would hold the sole expertise throughout the knowledge translation process (Davies et al., 2008), and knowledge users would only be consulted during the dissemination phase.

Unlike clinical settings, community-based settings do not rely solely on empirical evidence to inform practice change. Practice change involves multiple sources of knowledge, including experiential, cultural, contextual, ethical knowledge (Higgins et al., 2011; Thomas & Law,

2013). In this setting, the preferences, experiences, or insights related to practices of community members may be valuable sources of knowledge that are key for collaboration (Kothari & Armstrong, 2011). Experiential knowledge from persons with ID guided the IKT intervention in this project. This reveals the importance of including various sources of knowledge in guiding knowledge translation in community-based settings. Additionally, evaluating the knowledge translation process helped identify which knowledge sources, or combination of sources, informed implementation in community-based settings. This information may help the ongoing development of theories and models of knowledge translation in community-based settings (Salter & Kothari, 2016).

Second, there is not a single approach to knowledge translation that will apply to all settings (Grol, Wensing, et al., 2013). This is especially true in community-based settings where priorities, services, and the population receiving these services vary greatly. By tailoring interventions, not just research outputs (Grimshaw et al., 2012), interventions may become more readily accepted and adhered to (Harrison et al., 2010). Researchers may experience challenges in translating accessible knowledge to persons with ID (Spassiani et al., 2016). By engaging persons with ID in the knowledge translation process, research becomes more accessible and more accurately reflects the lived experiences of persons with ID (Kothari & Wathen, 2012; Spassiani et al., 2016). Collaborative frameworks such as IKT provide the opportunity for persons with ID to engage in research meaningfully (Dorozenko et al., 2016). They also provide the flexibility for researchers to modify methods as they gain contextual knowledge and a better understanding of the needs of persons with ID. Finally, researchers need to continue evaluating knowledge translation models and frameworks to appropriately use and leverage the expertise of persons with ID (Martin et al., 2010). This will benefit persons with ID by informing practice

and policy changes that appropriately support persons with ID (Spassiani et al., 2016). Increasing our understanding of how to involve knowledge users in IKT may also reduce the gap between research evidence and practice change (Jull et al., 2017).

Practice

Community-based organizations have limited access and capacity to understand research evidence and how to successfully implement change (Barwick et al., 2008; Dew & Boydell, 2017; Elsabbagh et al., 2014; Kothari & Armstrong, 2011). Through knowledge translation training programs, both agency personnel and knowledge users may enhance their understanding of the research process and the importance of implementing research evidence. However, community-based organizations often do not support personnel or persons with ID to engage in research. They may lack funding and time to engage in external training programs (Sheldon & Chilvers, 2000). For this reason, organizations need to revise existing policies, mandates, and job descriptions to include research as a priority (Martin et al., 2010). This will open the door to collaborations with research institutions that can provide missing knowledge translation expertise and scientific evidence to improve existing practices.

In addition to increasing the relevance and applicability of the intervention, involving persons with ID increased the face validity of the intervention. Both persons with ID and agency personnel were more interested in participating in project activities that were informed by or involved persons with ID. Community-based organizations may be more likely to engage in knowledge translation research if persons with ID are part of the research team. Finally, by further engaging in knowledge translation, community-based organizations may change the services and supports they invest in to facilitate the social inclusion of persons with ID.

Conclusion

The purpose of this dissertation was to identify barriers and facilitators to knowledge translation to bridge the gap between research evidence and current practices in community-based settings. A model, informed by knowledge translation theory for the healthcare setting, guides the intervention used in this project due to the paucity of available models for community settings. Findings in this dissertation reveal challenges in using healthcare models in community-based settings as these settings differ in their understanding and use of knowledge to inform change. We suggest modifications to existing knowledge translation models and provide recommendations to enhance further the inclusion of persons with ID in creating knowledge. A greater understanding of factors that promote or undermine the uptake of effective and meaningful change is of considerable significance for existing knowledge translation frameworks and theories. This may, in turn, inform change in policies and services to better support persons with ID.

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Appendix A: Procedure for Focus Groups with Front-line Staff and Caregivers

Protocole pour les groupes de discussion avec les aidants et le personnel de soutien

INFORMATION ADMINISTRATIVE

Détails:

- Durée: 1 heure et 30 minutes
- Lieu: agence de service, salle de rencontre privée
- 2 chercheurs:
    - Facilitateur: donner l'information initiale, procédures de consentement, faciliter la discussion
    - Administrateur: organiser les enregistreurs audio, prise de notes, chronométrage, etc.

Matériaux à préparer:

- Général:
    - Feuilles d'information et formulaires de consentement (2 copies par participant)
    - 2 enregistreurs audio

SCRIPT

Introduction (10 min)

1) BIENVENUE

Bonjour, je m'appelle Natasha Plourde et je suis chercheur à l'Université d'Ottawa. Ceci est _____. Il/Elle va m'aider avec la prise de notes durant la rencontre. Merci d'être venu aujourd'hui.

2) INFORMATION DE BASE

Avant de commencer, je vais vous expliquer ce que nous allons faire. Nous faisons de la recherche sur la sexualité. Nous cherchons à comprendre comment soutenir la sexualité des membres de l'AISO. Vos réponses vont nous aider à développer un plan pour aider le personnel à l'AISO afin qu'ils puissent mieux soutenir la sexualité des membres.

Aujourd'hui, nous allons faire un groupe de discussion. C'est un groupe de discussion sur vos pensées et expériences. Il n'y a pas de bonnes ou de mauvaises réponses. L'opinion et les

expériences de chacun et chacune sont importantes. Nous voulons entendre vos opinions même si elles sont différentes de celles des autres membres.

Nous allons enregistrer la rencontre aujourd'hui. Les enregistreurs audio sont placés là (*pointer les enregistreurs*). Nous allons enregistrer la discussion pour s'assurer d'avoir toute l'information qui est partagée.

Dans le report que nous allons écrire, nous n'allons pas inclure vos noms; ceux qui liront le rapport ne sauront pas que vous avez participé à ce groupe de discussion. Nous allons aussi partager vos pensées dans une plus grosse rencontre avec le personnel. Vous êtes invités à y participer aussi. Personne dans cette rencontre ne va savoir ce que vous avez dit, sauf si vous choisissez de le partager.

Avez-vous des questions?

N'hésitez surtout pas à me faire signe si vous avez des questions.

3) CONSENTEMENT

- *Donner deux copies du formulaire de consentement aux participants*
- *Faire un survol de l'information sur le formulaire de consentement et donner du temps aux participants pour qu'ils puissent lire le document*
- *Répondre aux questions des participants*
- *Mettre l'emphase sur le droit des participants de ne pas répondre et de retrait à tout moment*
- *Obtenir le consentement écrit*

4) INSTRUCTIONS DU GROUPE DE DISCUSSION

Ce qui suit va être dit en montrant la diapositive 'Instructions':

Voici les instructions à suivre durant la discussion aujourd'hui:

1. *Svp partagez vos pensées avec le groupe, si vous le voulez.*
    - Un rappel, vous n'êtes pas obligés de répondre à une question si vous ne le voulez pas.
2. *Svp parlez une personne à la fois.*
    - Nous demandons qu'une seule personne parle à la fois. Veuillez attendre votre tour et ne pas parler en même temps que quelqu'un d'autre.
3. *Svp ne pas partager l'information personnelle des gens dans le groupe aux gens à l'extérieur de ce groupe.*
    - Svp ne parlez pas aux gens à l'extérieur du groupe de ce qui est dit par les membres du groupe. Ne partagez pas le nom des membres du groupe.

DISCUSSIONS (1 heure)

Nous allons maintenant allumer les enregistreurs audio. *(Administrateur – allume les enregistreurs audio)*

Question de discussion 1 (25 min): Qualité du soutien reçu

Nous faisons une étude sur la sexualité. Nous cherchons à comprendre ce qui empêche la personne pour qui vous offrez du soutien de vivre sa sexualité. Vos réponses vont aider le personnel de l'AISO à offrir un meilleur soutien.

- Que fait le personnel/l'AISO pour vous aider la personne pour qui vous offrez du soutien à vivre sa sexualité?
    - Par exemple, est-ce qu'il y a des activités pour rencontrer des gens? Des activités à faire avec un copain/copine? Existe-il des programmes ou des règlements?
- Est-ce que le personnel/l'AISO fait quelque chose qui rend difficile pour la personne pour qui vous offrez du soutien de vivre sa sexualité?
- Que voudriez-vous que l'AISO fasse pour la personne pour qui vous offrez du soutien pour qu'elle puisse vivre sa sexualité?

Avez-vous d'autres commentaires sur le soutien offert?

Discussion 2 (50 min): Stratégies

Voici les différentes stratégies pour soutenir la sexualité des personnes pour qui vous offrez du soutien. (*Présenter chaque stratégie aux participants*).

Facilitateur – questions à poser au groupe:

- Que pensez-vous de cette stratégie? (*Poser la question pour chaque stratégie*)
- Est-ce qu'il y a des stratégies que l'AISO utilise déjà?
- Quelle stratégie est votre idée préférée? Pourquoi?
- Pouvez-vous penser à d'autres stratégies qui seraient utiles pour soutenir la sexualité de la personne pour qui vous offrez du soutien?
    - Les études démontrent que _____ est utile pour soutenir la sexualité. Comment est-ce que l'AISO pourrait commencer à utiliser cette stratégie?
    - Est-ce qu'il y a déjà quelque chose en place à l'AISO qui peut aider avec cette stratégie? *(Déterminer s'il y a des choses en place dans l'agence pour faciliter la mise en pratique de la stratégie)*
    - Est-ce qu'il y a déjà quelque chose en place à l'AISO qui peut empêcher d'utiliser cette stratégie? *(Déterminer s'il y a des choses en place dans l'agence pour empêcher la mise en pratique de la stratégie)*

Avez-vous d'autres commentaires sur ces stratégies?

6) CONCLUSIONS (5 min)

_____ *(administrateur)* a pris des notes durant la rencontre. Voici les messages clés que je vais partager dans la prochaine rencontre.

Pensez-vous que ce sont les messages clés de notre discussion? Devrais-je ajouter quelque chose?

Nous allons aussi partager vos pensées dans une rencontre avec le personnel de l'AISO. Vous êtes invités à y participer aussi. Cette rencontre aura lieu le 30 novembre de 13h à 14h à l'AISO.

Merci beaucoup d'avoir partagé vos pensées avec nous.

Appendix B1: Procedure for Focus Groups 1 with Adults with ID

Protocole pour le premier groupe de discussion

INFORMATION ADMINISTRATIVE

Détails:

- Durée: 45 minutes
- Lieu: agence de service, salle de rencontre privée
- 2 chercheurs:
    - Facilitateur: donner l'information initiale, procédures de consentement, faciliter la discussion
    - Administrateur: organiser les enregistreurs audio, prise de notes, chronométrage, etc.

Matériaux à préparer:

- Général:
    - Feuilles d'information et formulaires de consentement (2 copies par participant)
    - 2 enregistreurs audio

SCRIPT

Introduction (10 min)

1) BIENVENUE

Bonjour, je m'appelle Natasha Plourde et je suis chercheure à l'Université d'Ottawa. Ceci est _____. Il/Elle va m'aider avec la prise de notes durant la rencontre. Merci d'être venu aujourd'hui.

2) INFORMATION DE BASE

Avant de commencer, je vais vous expliquer ce que nous allons faire. Nous faisons de la recherche sur la sexualité. Nous cherchons à comprendre comment soutenir la sexualité des membres de l'AISO. Vos réponses vont nous aider à développer un plan pour aider le personnel à l'AISO afin qu'ils puissent mieux soutenir la sexualité des membres.

Aujourd'hui, nous allons faire un groupe de discussion. C'est un groupe de discussion sur vos pensées et expériences. Il n'y a pas de bonnes ou de mauvaises réponses. L'opinion et les expériences de chacun et chacune sont importantes. Nous voulons entendre vos opinions même si elles sont différentes de celles des autres membres.

Nous allons enregistrer la rencontre aujourd'hui. Les enregistreurs audios sont placés là (*pointer les enregistreurs*). Nous allons enregistrer la discussion pour s'assurer d'avoir toute l'information qui est partagée.

Dans le report que nous allons écrire, nous n'allons pas inclure vos noms; ceux qui liront le rapport ne sauront pas que vous avez participé à ce groupe de discussion. Nous allons aussi partager vos pensées dans une plus grosse rencontre avec le personnel. Vous êtes invités à y participer aussi. Personne dans cette rencontre ne va savoir ce que vous avez dit, sauf si vous choisissez de le partager.

Avez-vous des questions?

N'hésitez surtout pas à me faire signe si vous avez des questions.

3) CONSENTEMENT

- *Donner deux copies du formulaire de consentement aux participants*
- *Faire un survol de l'information sur le formulaire de consentement et donner du temps aux participants pour qu'ils puissent lire le document*
- *Répondre aux questions des participants*
- *Mettre l'emphase sur le droit des participants de ne pas répondre et de retrait à tout moment*
- *Obtenir le consentement écrit*

4) INSTRUCTIONS DU GROUPE DE DISCUSSION

Ce qui suit va être dit en montrant la diapositive 'Instructions':

Voici les instructions à suivre durant la discussion aujourd'hui:

1. *Svp partagez vos pensées avec le groupe, si vous le voulez.*
    - Un rappel, vous n'êtes pas obligés de répondre à une question si vous ne le voulez pas.
2. *Svp parlez une personne à la fois.*
    - Nous demandons qu'une seule personne parle à la fois. Veuillez attendre votre tour et ne pas parler en même temps que quelqu'un d'autre.
3. *Svp ne pas partager l'information personnelle des gens dans le groupe aux gens à l'extérieur de ce groupe.*
    - Svp ne parlez pas aux gens à l'extérieur du groupe de ce qui est dit par les membres du groupe. Ne partagez pas le nom des membres du groupe.

5) DISCUSSION (30 min)

Nous allons maintenant allumer les enregistreurs audios. *(Administrateur – allume les enregistreurs audio)*

Question de discussion : Qualité du soutien reçu

Nous faisons une étude sur la sexualité. Nous cherchons à comprendre comment l'AISO soutient votre sexualité et ce qui vous empêche de vivre votre sexualité. Vos réponses vont aider le personnel de l'AISO à offrir un meilleur soutien.

- Que fait le personnel/l'AISO pour vous aider à vivre votre sexualité?
    - Par exemple, est-ce qu'il y a des activités pour rencontrer des gens? Des activités à faire avec un copain/copine? Existe-il des programmes ou des règlements?
- Est-ce que le personnel/l'AISO fait quelque chose qui rend ça difficile de vivre votre sexualité?
- Que voudriez-vous que l'AISO fasse pour vous aider à vivre votre sexualité?

Avez-vous d'autres commentaires sur le soutien reçu?

6) CONCLUSIONS (5 min)

_____ *(administrateur)* a pris des notes durant la rencontre. Voici les messages clés que je vais partager dans la prochaine rencontre.

Pensez-vous que ce sont les messages clés de notre discussion? Devrais-je ajouter quelque chose?

Nous allons nous rencontrer dans deux semaines au même endroit et à la même heure pour continuer notre discussion.

Merci beaucoup d'avoir partagé vos pensées avec nous.

Appendix B2: Procedure for Focus Groups 2 with Adults with ID

Protocole pour le deuxième groupe de discussion

INFORMATION ADMINISTRATIVE

Détails:

- Durée: 45 minutes
- Lieu: agence de service, salle de rencontre privée
- 2 chercheurs:
    - Facilitateur: donner l'information initiale, procédures de consentement, faciliter la discussion
    - Administrateur: organiser les enregistreurs audios, prise de notes, chronométrage, etc.

Matériaux à préparer:

- Général:
    - Feuilles d'information et formulaires de consentement (2 copies par participant)
    - 2 enregistreurs audios

SCRIPT

Introduction (10 min)

1) BIENVENUE

Bonjour, je m'appelle Natasha Plourde et je suis chercheure à l'Université d'Ottawa. Ceci est _____. Il/Elle va m'aider avec la prise de notes durant la rencontre. Merci d'être venu aujourd'hui.

2) INFORMATION DE BASE

Avant de commencer, je vais vous expliquer ce que nous allons faire. Nous faisons de la recherche sur la sexualité. Nous cherchons à comprendre comment soutenir la sexualité des membres de l'AISO. Vos réponses vont nous aider à développer un plan pour aider le personnel à l'AISO afin qu'ils puissent mieux soutenir la sexualité des membres.

Aujourd'hui, nous allons faire un groupe de discussion. C'est un groupe de discussion sur vos pensées et expériences. Il n'y a pas de bonnes ou de mauvaises réponses. L'opinion et les expériences de chacun et chacune sont importantes. Nous voulons entendre vos opinions même si elles sont différentes de celles des autres membres.

Nous allons enregistrer la rencontre aujourd'hui. Les enregistreurs audios sont placés là (*pointer les enregistreurs*). Nous allons enregistrer la discussion pour s'assurer d'avoir toute l'information qui est partagée.

Dans le report que nous allons écrire, nous n'allons pas inclure vos noms; ceux qui liront le rapport ne sauront pas que vous avez participé à ce groupe de discussion. Nous allons aussi partager vos pensées dans une plus grosse rencontre avec le personnel. Vous êtes invités à y participer aussi. Personne dans cette rencontre ne va savoir ce que vous avez dit, sauf si vous choisissez de le partager.

Avez-vous des questions?

N'hésitez surtout pas à me faire signe si vous avez des questions.

3) CONSENTEMENT

- *Donner deux copies du formulaire de consentement aux participants*
- *Faire un survol de l'information sur le formulaire de consentement et donner du temps aux participants pour qu'ils puissent lire le document*
- *Répondre aux questions des participants*
- *Mettre l'emphase sur le droit des participants de ne pas répondre et de retrait à tout moment*
- *Obtenir le consentement écrit*

4) INSTRUCTIONS DU GROUPE DE DISCUSSION

Ce qui suit va être dit en montrant la diapositive 'Instructions':

Voici les instructions à suivre durant la discussion aujourd'hui:

4. *Svp partagez vos pensées avec le groupe, si vous le voulez.*
    - Un rappel, vous n'êtes pas obligés de répondre à une question si vous ne le voulez pas.
5. *Svp parlez une personne à la fois.*
    - Nous demandons qu'une seule personne parle à la fois. Veuillez attendre votre tour et ne pas parler en même temps que quelqu'un d'autre.
6. *Svp ne pas partager l'information personnelle des gens dans le groupe aux gens à l'extérieur de ce groupe.*
    - Svp ne parlez pas aux gens à l'extérieur du groupe de ce qui est dit par les membres du groupe. Ne partagez pas le nom des membres du groupe.

DISCUSSION (30 min)

Nous allons maintenant allumer les enregistreurs audios. *(Administrateur – allume les enregistreurs audio)*

Nous nous sommes rencontrés il y a deux semaines pour discuter de la qualité du soutien offert par l'AISO. Aujourd'hui nous allons parler de stratégies que l'AISO pourrait utiliser.

Questions de discussion : Considérations pour la mise en oeuvre *(stratégies 1 à 3)*

Voici les stratégies que nous avons identifiées (*présenter une stratégie à la fois).*

Comment est-ce que l'AISO pourrait commencer à utiliser une de ces stratégies (*nommer une stratégie à la fois et poser les questions suivantes)*?

- Est-ce qu'il existe quelque chose comme ça déjà à l'AISO? Est-ce que ça fonctionne bien? Pourquoi?
- Qui peut aider pour qu'on commence à utiliser cette stratégie? Que faut-il changer? (*Déterminer s'il y a des choses en place dans l'agence pour faciliter la mise en pratique de la stratégie)*

- Est-ce qu'il y a déjà quelque chose à l'AISO qui peut empêcher d'utiliser cette stratégie? Quel sont les obstacles à cette stratégie? Est-ce qu'il y a quelque chose à l'AISO qui ne fonctionne pas? Pourquoi?
  (Déterminer s'il y a des choses en place dans l'agence pour empêcher la mise en pratique de la stratégie)

- Pouvez-vous penser à d'autres stratégies qui seraient utiles pour soutenir votre sexualité?

Avez-vous d'autres commentaires sur ces stratégies?

<u>6) CONCLUSIONS (5 min)</u>

_____ *(administrateur)* a pris des notes durant la rencontre. Voici les messages clés que je vais partager dans la prochaine rencontre.

Pensez-vous que ce sont les messages clés de notre discussion? Devrais-je ajouter quelque chose?

Nous allons nous rencontrer dans deux semaines au même endroit et à la même heure pour continuer notre discussion.

Merci beaucoup d'avoir partagé vos pensées avec nous.

Appendix B3: Procedure for Focus Groups 3 with Adults with ID

Protocole pour le troisième groupe de discussion

INFORMATION ADMINISTRATIVE

Détails:

- Durée: 45 minutes
- Lieu: agence de service, salle de rencontre privée
- 2 chercheurs:
    - Facilitateur: donner l'information initiale, procédures de consentement, faciliter la discussion
    - Administrateur: organiser les enregistreurs audio, prise de notes, chronométrage, etc.

Matériaux à préparer:

- Général:
    - Feuilles d'information et formulaires de consentement (2 copies par participant)
    - 2 enregistreurs audio

SCRIPT

Introduction (10 min)

1) BIENVENUE

Bonjour, je m'appelle Natasha Plourde et je suis chercheur à l'Université d'Ottawa. Ceci est _____. Il/Elle va m'aider avec la prise de notes durant la rencontre. Merci d'être venu aujourd'hui.

2) INFORMATION DE BASE

Avant de commencer, je vais vous expliquer ce que nous allons faire. Nous faisons de la recherche sur la sexualité. Nous cherchons à comprendre comment soutenir la sexualité des membres de l'AISO. Vos réponses vont nous aider à développer un plan pour aider le personnel à l'AISO afin qu'ils puissent mieux soutenir la sexualité des membres.

Aujourd'hui, nous allons faire un groupe de discussion. C'est un groupe de discussion sur vos pensées et expériences. Il n'y a pas de bonnes ou de mauvaises réponses. L'opinion et les expériences de chacun et chacune sont importantes. Nous voulons entendre vos opinions même si elles sont différentes de celles des autres membres.

Nous allons enregistrer la rencontre aujourd'hui. Les enregistreurs audios sont placés là (*pointer les enregistreurs*). Nous allons enregistrer la discussion pour s'assurer d'avoir toute l'information qui est partagée.

Dans le report que nous allons écrire, nous n'allons pas inclure vos noms; ceux qui liront le rapport ne sauront pas que vous avez participé à ce groupe de discussion. Nous allons aussi partager vos pensées dans une plus grosse rencontre avec le personnel. Vous êtes invités à y participer aussi. Personne dans cette rencontre ne va savoir ce que vous avez dit, sauf si vous choisissez de le partager.

Avez-vous des questions?

N'hésitez surtout pas à me faire signe si vous avez des questions.

3) CONSENTEMENT

- *Donner deux copies du formulaire de consentement aux participants*
- *Faire un survol de l'information sur le formulaire de consentement et donner du temps aux participants pour qu'ils puissent lire le document*
- *Répondre aux questions des participants*
- *Mettre l'emphase sur le droit des participants de ne pas répondre et de retrait à tout moment*
- *Obtenir le consentement écrit*

4) INSTRUCTIONS DU GROUPE DE DISCUSSION

Ce qui suit va être dit en montrant la diapositive 'Instructions':

Voici les instructions à suivre durant la discussion aujourd'hui:

7. *Svp partagez vos pensées avec le groupe, si vous le voulez.*
    - Un rappel, vous n'êtes pas obligés de répondre à une question si vous ne le voulez pas.
8. *Svp parlez une personne à la fois.*
    - Nous demandons qu'une seule personne parle à la fois. Veuillez attendre votre tour et ne pas parler en même temps que quelqu'un d'autre.
9. *Svp ne pas partager l'information personnelle des gens dans le groupe aux gens à l'extérieur de ce groupe.*
    - Svp ne parlez pas aux gens à l'extérieur du groupe de ce qui est dit par les membres du groupe. Ne partagez pas le nom des membres du groupe.

5) DISCUSSION (30 min)

Nous allons maintenant allumer les enregistreurs audios. *(Administrateur – allume les enregistreurs audio)*

Durant notre dernière rencontre, nous avons discutés de stratégies qui pourraient être bonnes ou mauvaises à l'AISO.

Questions de discussion : Considérations pour la mise en oeuvre *(stratégies 4 et 5)*

Voici deux nouvelles stratégies (*nommer une stratégie à la fois et poser les questions suivantes).*

Comment est-ce que l'AISO pourrait commencer à utiliser une de ces stratégies?

- Est-ce qu'il existe quelque chose comme ça déjà à l'AISO? Est-ce que ça fonctionne bien? Pourquoi?
- Qui peut aider pour qu'on commence à utiliser cette stratégie? Que faut-il changer? (*Déterminer s'il y a des choses en place dans l'agence pour faciliter la mise en pratique de la stratégie)*

- Est-ce qu'il y a déjà quelque chose à l'AISO qui peut empêcher d'utiliser cette stratégie? Quel sont les obstacles à cette stratégie? Est-ce qu'il y a quelque chose à l'AISO qui ne fonctionne pas? Pourquoi?
  (Déterminer s'il y a des choses en place dans l'agence pour empêcher la mise en pratique de la stratégie)

- Pouvez-vous penser à d'autres stratégies qui seraient utiles pour soutenir votre sexualité?

Avez-vous d'autres commentaires sur ces stratégies?

<u>6) CONCLUSIONS (5 min)</u>

_____ *(administrateur)* a pris des notes durant la rencontre. Voici les messages clés que je vais partager dans la prochaine rencontre.

Pensez-vous que ce sont les messages clés de notre discussion? Devrais-je ajouter quelque chose?

Nous allons aussi partager vos pensées dans une plus grosse rencontre avec le personnel. Vous êtes invités à y participer aussi. Cette rencontre aura lieu à l'AISO le 30 novembre de 13h-14h.

Merci beaucoup d'avoir partagé vos pensées avec nous.

Appendix B4: Working Document for Focus Group Participants

Stratégies prometteuses pour soutenir la sexualité des adultes ayant une déficience intellectuelle dans des agences de services communautaires

Titre: Évaluation d'un processus de transfert des connaissances dans des agences de services communautaires : Mise en œuvre de stratégies pour offrir du soutien aux personnes ayant une déficience intellectuelle pour vivre une sexualité épanouie

Chercheurs: Natasha Plourde, B.Sc., Candidate au doctorat
Virginie Cobigo, Ph.D., C.Psych., Professeure agrégée

Ce document est un brouillon des stratégies qui seront dans un rapport visant à informer la prise de décisions des parties prenantes. Il résume les stratégies ayant le meilleur niveau de preuves, identifiés dans la littérature scientifique, pour soutenir la sexualité des adultes ayant une déficience intellectuelle (DI). Ces stratégies et les résultats de la consultation seront discutées en durant une prochaine rencontre d'une demi-journée avec toutes les parties prenantes qui aura lieu à l'AISO le 30 novembre. Vous êtes invités à participer à cette rencontre.

Stratégie 1 et 2: Programmes d'éducation sexuelle pour les adultes ayant une DI

Source: Garwood, M. et McCabe, M. P. (2000). Impact of sex education programs on sexual knowledge and feelings of men with mild intellectual disability, *Education and Training in Mental Retardation and Developmental Disabilities,* 35(*3*), 269-283.

Niveau de preuve: 2.5

Cette étude présente deux programmes d'éducation sexuelle visant à augmenter les connaissances et émotions positives des hommes ayant une DI envers leur sexualité. Les connaissances des participants ont été mesurées avant et après chaque programme d'éducation sexuelle.

Stratégie 1 − Co-Care : 10 sessions hebdomadaires, durant 2h chaque avec 2 instructeurs (un de chaque sexe)

Sujets : émotions, langage corporel, habiletés sociales, cycle de la vie humaine, puberté, conscience du corps, comportement privé et publique, relations sexuelles, conception, grossesses et accouchement, contraception (et ITSS), menstruation et comportement de protection

Résultats clés:

- Il y a eu une **augmentation significative des connaissances** par rapport à l'amitié, le mariage, relations sexuelles, la contraception, la grossesse et l'homosexualité. Il y a eu une faible augmentation des connaissances sur l'identification des parties du corps, les ITSS et les interactions sexuelles.

- ➔ Il y a eu **plus d'émotions positives** suite au programme au sujet des amitiés avec les femmes et caresser quelqu'un du sexe opposé. Cependant, les émotions négatives envers une copine, la masturbation, le sex oral-génital et la pénétration n'ont pas changé suivant le programme.

Stratégie 2 − Family Planning Victoria (FPV) : 6 sessions hebdomadaires, durant 1h chaque avec 1 instructeur

Sujets : conscience de soi, émotions, conscience du corps, comportement privé et publique, relations sexuelles, contraception, amitié et relations, SIDA et comportement de protection

Résultats clés :

- ➔ Il y a eu une **augmentation significative des connaissances** par rapport aux relations sexuelles, la contraception, la grossesse et les ITSS.
- ➔ Il y a eu **plus d'émotions positives** suite au programme au sujet des amitiés avec les femmes et caresser quelqu'un du sexe opposé. Cependant, les émotions négatives envers une copine, la masturbation, le sex oral-génital et la pénétration n'ont pas changé suivant le programme.

Stratégie 3 : Programme d'éducation sexuelle pour les adultes ayant une DI

Source: Caspar, L. A. et Glidden, L. M. (2001). Sexuality Education for Adults with Developmental Disabilities, *Education and Training in Mental Retardation and Developmental Disabilities*, 36 (*2*), 172-177

Niveau de preuve: 2

Cette étude présente un programme d'éducation sexuelle visant à augmenter les connaissances sexuelles d'adultes ayant une DI dans des services résidentiels. Ce programme de six sessions, durant 2h30 à 3h chacune, inclut un curriculum, des diagrammes, des documents, des vidéos, et des tests. Les documents incluent des informations sur les infections transmises sexuellement et par le sang et les méthodes de contraception. Les diagrammes présentent l'anatomie des organes reproductifs masculins et féminins, le cycle menstruel, *Circle Concept* qui une méthode qui permet d'identifier les personnes qui entourent l'individu avec une DI selon leur niveau de familiarité, et une feuille de *Planned Parenthood* présentant différentes méthodes contraceptives. Des modèles de condoms et d'organes reproductifs *Jackson* sont aussi utilisés. Une méthode pré et post test a été utilisée afin de démontrer si le programme augmente les connaissances sexuelles et change les attitudes des personnes ayant une DI.

Résultats clés :

- ➔ Les **connaissances factuelles sur la sexualité ont augmenté** significativement après la participation au programme d'éducation sexuelle.
- ➔ Les **connaissances subjectives liées aux attitudes, valeurs, croyances et opinions envers sa propre sexualité ont augmenté** significativement après la participation au programme d'éducation sexuelle.
- ➔ Le **programme a été très bien reçu par les participants**. Le sujet de la sexualité était une grande motivation à participer au programme. Il n'y a pas eu d'autres incitations à la participation autre que le sujet. Par exemple, dû à des difficultés à organiser les activités dans

l'agence de service, les participants manquaient souvent des activités sociales et des loisirs afin de participer aux sessions du programme.

Stratégie 4 : Nominal Group Technique (NGT)

Sources: Friedman, C., Arnold, C. K., Owen, A., et Sandman, L. (2014). "Remember our voices are our tools:" Sexual self-advocacy as defined by people with intellectual and developmental disabilities, *Sexuality and Disability*, 32, 515-532.

Owen, A., Arnold, K., Friedman, C., et Sandman, L. (2016). Nominal Group Technique: An accessible method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities, *Qualitative Social Work*, 15(*2*), 175-189.

Niveau de preuve: 2

Cette étude présente le *Nominal Group Technique* (NGT) utilisé pour explorer comment les personnes ayant une DI définissent et vivent leur sexualité dans le contexte de leur identité en tant que défenseurs de leurs droits. NGT, une méthode de recherche-action participative (RAP), est composée de discussions non-critiques, structurées et simples à comprendre pour les personnes ayant une DI. Des activités ont eu lieu avant le NGT tel que des jeux de rôles sur les relations et la sécurité et la présentation des droits liés à la sexualité pour les personnes ayant une DI afin de familiariser les participants aux questions du NGT.

Étapes de la technique :

1. Donner une question ou un sujet aux participants et du temps de réflexion;
2. Demander aux participants d'écrire leurs réponses sur un papier;
3. Demander aux participants de partager leurs idées, un à la fois et une idée à la fois;
4. Prendre en note les idées sur un tableau et combiner les idées similaires sous des thèmes;
5. Discuter les thèmes avec le groupe, restructurer et valider les thèmes; et
6. Voter sur les thèmes pour donner un ordre de priorité.

Résultats clés :

- ➔ Méthode qui permet aux **personnes ayant une DI de partager leurs expériences et opinions dans un environnement sans-jugement**
- ➔ Les participants ont décrit que la défense de droits sexuels (*sexual self-advocacy*) est associé aux connaissances et au respect envers soi-même, au respect envers les autres, à la prise de décision, prendre la parole, le respect de leurs droits, obtenir de l'information, des relations saines, et l'interdépendance.
- ➔ Facilitateurs identifiés envers la défense des droits sexuels : accroître l'accès à l'information et aux services de santé sexuelle, enlever les obstacles systémiques, éduquer les autres, augmenter l'accès au counseling, et développer des opportunités pour l'expression sexuelle.

Stratégie 5 : Éducation sexuelle donné par les pairs

Source: Frawley, P. & Bigby, C. (2014). 'I'm in their shoes': Experiences of peer educators in sexuality and relationship education, *Journal of Intellectual and Developmental Disabilities*, 39(*2*), 167-176.

Niveau de preuve: 1.5

Cette étude présente un programme d'éducation sexuelle, *Living Safer Sexual Lives : Respectful Relationship* (LSSL :RR), développé à partir du ancien programme *Living Safer Sexual Lives*, où le co-facilitateur du programme est un adulte ayant une DI. Ce programme a été développé à partir de 25 histoires de vie d'adultes ayant une DI.

LSSL :RR :

- Le programme comporte 4 sessions : 1. Parler de la sexualité et des relations sexuelles, 2. Avoir des droits et être en sécurité, 3. Relations respectueuses, et 4. Les hommes et les relations respectueuses.
- Chaque session utilise une des 25 histoires
- Chaque session permet aux participants de faire des activités et de réfléchir sur de thèmes clés dont les droits dans une relation, l'intimité et les forces de chacun
- Les participants sont encouragés de choisir un partenaire dans l'apprentissage dans leur cercle de soutien. Ce partenaire a le rôle de soutenir l'apprentissage de l'adulte ayant une DI dans le programme et apprend à la fois comment soutenir l'adulte pour qu'il ait des relations respectueuses.
- Le programme vise aussi l'engagement communautaire en formant des membres du personnel d'agences de service comme co-facilitateur.

Résultats clés :

- ➔ Les participants ont déclaré qu'il y avait une **augmentation de leurs connaissances** par rapport à leurs droits dans des relations, aux services et ressources disponibles pour les soutenir dans des relations, et au niveau de la confiance à parler du sujet de relations intimes avec les autres et d'offrir du soutien.
- ➔ Les pairs qui co-facilitent le programme ont rapportés que l'éducation donnée par les pairs offrait un sentiment d'autonomisation, aide à soutenir les autres, augmente leur crédibilité, et a créé des opportunités d'apprendre de nouvelles choses sur les relations respectueuses, les ressources communautaires et de nouvelles habiletés.
- ➔ **L'éducation donné par les pairs est perçue et vécue comme étant une approche bénéfique**.

Appendix C: Pre-Structured Case Summary Outline for Focus Groups

Pre-Structured Case Summary Outline

I. Quality of existing supports towards sexuality of persons with ID
   a. Supports provided by the agency (e.g., personnel, activities, policies, procedures, rules)
   b. Barriers towards the sexuality of persons with ID within the agency
   c. Improvements to existing supports

II. An overview of each strategy identified in the scoping review
   a. Perspectives, experiences and preferences for parts or the entirety of the identified strategies
   b. Additional strategies to consider

III. Strategy implementation considerations related to the service agency
   a. Facilitators
   b. Barriers

Appendix D: Evidence Brief on Strategies to Support Sexuality of Persons with ID

Stratégies prometteuses pour soutenir la sexualité des adultes ayant une déficience intellectuelle

Résumé de preuves pour l'Association pour l'intégration sociale d'Ottawa

30 novembre, 2017

Auteurs: Natasha Plourde et Virginie Cobigo

uOttawa

Ce résumé de preuves a été développé pour l'Association pour l'intégration sociale d'Ottawa, en tant que document de recherche pour la thèse doctorale de Natasha Plourde à l'Université d'Ottawa

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Plourde, N. & Cobigo, V. (2017). *Stratégies prometteuses pour soutenir la sexualité d'adultes ayant une déficience intellectuelle : résumé de preuves pour l'Association pour l'intégration sociale d'Ottawa*. (rapport non publié). Université d'Ottawa, Ottawa, Ontario.

Préface

Ce rapport vise à informer la prise de décisions des parties prenantes. Il résume les stratégies ayant le meilleur niveau de preuves pour soutenir la sexualité des adultes ayant une déficience intellectuelle (DI) ainsi que les considérations pratiques pour la mise en œuvre de ces stratégies à l'Association pour l'intégration sociale d'Ottawa (AISO). Ce rapport sert de document de référence pour une rencontre d'une demi-journée qui aura lieu à l'AISO le 30 novembre. Cette rencontre vise à inclure ceux qui ont été impliqués dans la création du résumé de preuves et les gens pour qui ce sujet est d'importance particulière. De plus, ce rapport servira à informer les autres parties prenantes et à les engager dans la prise de décisions sur comment mieux soutenir la sexualité d'adultes ayant une DI. Le but est d'assurer une transparence des informations découlant de la littérature scientifique et des consultations afin d'informer la prise de décisions.

Comment utiliser le rapport

Veuillez lire les stratégies présentées dans le rapport ainsi que les avantages et limites associés à chacune des 5 stratégies (pages 8 à 12 et l'annexe 1). Pour chaque stratégie, il y a une boîte pour vos commentaires. Veuillez noter vos commentaires dans cette boîte et amener ce document au groupe de discussion entre parties prenantes. Ces commentaires seront très utiles lors de la prise de décisions entre parties prenantes.

La structure du rapport

Le résumé du rapport souligne les messages clés et offre un sommaire de chaque section du rapport au complet. Bien que cela entraîne une réplication de l'information, le résumé demeure utile pour ceux à qui s'adresse ce rapport mais qui n'auront pas le temps de le lire au complet. Par la suite, nous présentons la problématique et les facteurs liés à celle-ci. Nous continuons le rapport avec la présentation de 5 différentes stratégies pour soutenir la sexualité des personnes recevant un service à l'AISO et de conseils généraux pour la mise en œuvre des stratégies à l'AISO. Nous terminons avec les résultats des consultations avec les parties prenantes et des étapes à suivre. En annexe vous retrouverez des informations supplémentaires.

La préparation du rapport

Le résumé de preuves rassemble des preuves scientifiques mondiales et les résumés de consultations avec les personnes recevant un service de l'AISO, le personnel et les aidants. Nous avons consulté la littérature scientifique pour identifier des preuves pertinentes, les impacts des différentes stratégies, les obstacles à la mise en œuvre des stratégies, et les considérations pour l'implantation des stratégies. Nous ajoutons des informations supplémentaires liées à la mise en œuvre des stratégies tirées d'études non incluses dans la recension et de documents pertinents.

Limites du rapport

Ce résumé de preuves est basé sur les écrits scientifiques. Lorsque l'information n'était pas disponible dans les articles inclus dans le rapport, nous avons tenté de compléter l'information en utilisant d'autres articles et documents pertinents, et en communiquant avec des experts. Faire un résumé de preuves demande de porter un jugement sur les preuves à inclure dans le résumé, la qualité des preuves, comment interpréter les résultats et comment les présenter. Bien que nous ayons tenté d'être transparents dans nos jugements, un biais peut avoir été introduit par les auteurs et de ceux qui ont révisé le document.

Résumé

La sexualité est un droit fondamental pour les personnes ayant une déficience intellectuelle (DI). Malheureusement, les personnes ayant une DI rencontrent plusieurs obstacles envers leur sexualité. Ceux-ci incluent des attitudes négatives envers leur sexualité, une vulnérabilité accrue à l'agression sexuelle, un manque d'expériences et d'éducation sexuelle, et un manque de formation des membres du personnel. Des stratégies existent dans les écrits scientifiques pour réduire les obstacles à la sexualité et soutenir la sexualité des personnes recevant un service mais celles-ci ne sont pas actuellement utilisées. Les 5 stratégies identifiées qui ont le plus haut niveau de preuves incluent (veuillez consulter les pages 8 à 12 et l'annexe 1 pour plus de détails sur les stratégies):

#1. La méthode *Nominal Group Technique* (NGT) permet aux adultes ayant une déficience intellectuelle de discuter de sujets tabous comme la sexualité, identifier des thèmes clés et prioriser les thèmes;

#2 et 3. Deux programmes d'éducation sexuelle pour les hommes ayant une DI visant à augmenter les connaissances et les émotions positives;

#4. Un programme d'éducation sexuelle pour les adultes ayant une DI visant à augmenter les connaissances factuelles et les attitudes, croyances, et opinions envers la sexualité; et

#5. Un programme d'éducation sexuelle pour les adultes ayant une DI sur les relations respectueuses impliquant l'enseignement par les pairs.

Il y a plusieurs conseils généraux à la mise en œuvre de ces stratégies à l'Association pour l'intégration sociale d'Ottawa (AISO) :

1. Il existe **un besoin de formation, de ressources, et de procédures organisationnelles ainsi que des politiques claires pour les membres du personnel et les aidants** afin de soutenir la sexualité des personnes recevant un service. Il est important de recruter des membres du personnel qui ont les connaissances ou habiletés nécessaires pour la mise en œuvre de la stratégie choisie ou de recruter des membres qui sont motivés à recevoir la formation nécessaire. Au niveau de la motivation, il faut aussi prendre en compte la disponibilité du personnel dans la sélection de la stratégie. L'AISO pourrait aussi obtenir du soutien de personnes externes ou de bénévoles pour la mise en œuvre de la stratégie et envisager des partenariats avec des ressources dans la communauté (ex : Planned Parenthood, Centre d'aide et de lutte contre les agressions à caractère sexuel (CALACS)).
2. **Plusieurs programmes d'éducation sexuelle pour les personnes recevant un service existent mais ils ont plusieurs lacunes**. L'éducation sexuelle se concentre surtout sur les conséquences négatives de la sexualité (par exemple, les agressions sexuelles, les grossesses non-planifiées) ce qui entrave le développement de l'identité et des relations sexuelles. De plus, l'éducation sexuelle doit non seulement mettre l'accent sur l'augmentation des connaissances, mais aussi sur le développement d'habiletés qui peuvent être généralisées à des situations de vie réelles.
3. Il faut **favoriser l'autonomie des personnes recevant un service et impliquer les personnes dans la prise de décisions**. Le but n'est pas de former le personnel et les aidants afin de prendre des décisions pour la personne recevant un service; mais plutôt de favoriser l'autonomie de la personne recevant un service pour qu'elle puisse solliciter elle-même du soutien envers sa sexualité. Les personnes recevant un service ont une vulnérabilité accrue. Il faut trouver une

façon de favoriser **un équilibre entre le besoin de protection de la personne recevant un service avec ses droits d'avoir une sexualité épanouie**. Pourtant, les stratégies de protection (par exemple, limiter les activités et le temps privé) ne sont pas suffisantes afin d'empêcher les agressions sexuelles. Les personnes recevant un service ont besoin d'apprendre comment se protéger elles-mêmes. Il faut alors travailler avec la personne recevant un service pour identifier les risques et développer un plan d'action qui reflète les aspects positifs potentiels et ses priorités.

4. **La stratégie choisie doit être adaptée selon les connaissances, intérêts, et besoins de la personne recevant un service**. Cette adaptation peut être au niveau du contenu de la stratégie (par exemple, se concentrer sur les notions de base de la sexualité comme la différence entre les sexes, et non sur les notions plus complexes comme la communication dans un couple) ou au niveau du format (par exemple, avoir moins de participants dans un groupe, ou faire du un à un). La **stratégie peut aussi être adaptée pour des raisons organisationnelles** (par exemple, réduire les coûts). Il est important de consulter les personnes recevant les services et leurs aidants pour toute modification aux stratégies et d'être transparent dans les raisons pour lesquelles une stratégie n'a pas été possible.

Les consultations ont démontré que l'AISO joue un rôle important dans la vie quotidienne des personnes recevant un service et les participants des consultations rapportent beaucoup d'humanité, de soutien et de motivation à l'AISO. Au niveau des stratégies, ils ont une préférence envers la stratégie #1, le NGT, et la stratégie #5, l'enseignement par les pairs. En général, ils aimeraient une combinaison de stratégies, que le contenu et le format soient adaptés selon la personne, et que la stratégie soit visuelle et interactive.

Les prochaines étapes sont de discuter du choix d'une stratégie ou une combinaison de stratégies pour mieux soutenir la sexualité des personnes recevant un service; de modifier, élargir, ou sélectionner des éléments d'une stratégie afin de mieux répondre aux besoins et aux ressources disponibles à l'AISO (par exemple, disponibilité, coûts, locaux); ou de créer une nouvelle stratégie à partir des informations dans le résumé de preuves, des consultations et des discussions durant le dialogue entre parties prenantes (par exemple, le développement d'une politique organisationnelle ou une formation du personnel). Cela s'inscrit dans un projet de recherche qui vise à mieux comprendre comment un organisme comme l'AISO peut utiliser les données scientifiques pour informer le changement de pratiques. L'étudiante va soutenir l'AISO dans le développement et l'exécution de la stratégie afin de mieux soutenir la sexualité des personnes recevant un service.

À noter que ces informations visent à favoriser une discussion et des jugements informés par les meilleures preuves disponibles en préparation pour une rencontre avec les membres du personnel, l'équipe de gestion, les personnes recevant un service, et les aidants le 30 novembre au siège social de l'AISO. Ces informations ne visent pas à promouvoir une stratégie en particulier ou clore la discussion sur comment soutenir la sexualité des adultes ayant une DI.

Stratégies prometteuses pour soutenir la sexualité d'adultes ayant une déficience intellectuelle : résumé de preuves pour l'Association pour l'intégration sociale d'Ottawa

La problématique

La sexualité joue un rôle important dans la vie des adultes ayant une déficience intellectuelle (DI). Elle est associée au bien-être et à la santé physique[1] et les relations sexuelles ont une haute importance pour les adultes ayant une DI[2-5]. La recherche a démontré que les adultes ayant une DI ont les mêmes désirs et rêves sexuels que les personnes n'ayant pas une DI[6].

La *Convention relative aux droits des personnes handicapées* (2006) des Nations Unies spécifie que les personnes handicapées ont non seulement le droit au mariage, à fonder une famille, et à maintenir leur fertilité (Article 23), mais aussi d'avoir accès à des soins en matières de santé sexuelle et génésique (Article 25)[7]. Les adultes ayant une DI ont le droit d'exprimer leur sexualité et de choisir leurs expériences et de ne plus être exclus d'une vie sexuelle épanouie[8].

Facteurs à la base de la problématique

Malgré les réformes législatives pour promouvoir les droits des personnes ayant une DI à connaître une vie sexuelle[7], il existe plusieurs obstacles envers leur sexualité. Premièrement, il existe plusieurs attitudes négatives et des fausses croyances envers la sexualité des personnes ayant une DI. D'un côté, ils peuvent être perçus comme étant asexuels, enfantins et ayant besoin de protection[9-12]; de l'autre côté, ils sont parfois considérés hypersexuels et incapables de contrôler leurs pulsions[6.9, 12-13].

Ces attitudes peuvent découler du haut taux d'agressions sexuelles envers les personnes ayant une DI en comparaison aux personnes sans DI[14]. Une étude a démontré que les personnes ayant une DI étaient presque 3 fois plus à risque d'agression sexuelle en comparaison aux personnes sans DI[15]. On estime que jusqu'à 90% des personnes présentant une DI ont été victimes d'agression sexuelle[16], et que parmi les victimes, 80% d'entre elles ont été victimes de multiples agressions[17]. La vulnérabilité accrue des personnes ayant une DI aux agressions sexuelles peut être expliquée par l'isolement social et la dépendance envers autrui de ce groupe, l'incapacité de reconnaître l'acte comme étant une agression sexuelle, la fréquence des contacts physiques avec des professionnels, et certaines personnes ayant une DI ont moins de connaissances et d'expériences en matière de la sexualité que les personnes sans DI[6]. Étant donné cette vulnérabilité accrue[18,19], il est particulièrement difficile pour le personnel de soutien de contrebalancer les droits des personnes ayant une DI à vivre une sexualité avec leur devoir de protéger les usagers contre les agressions[20-23]. Malheureusement, le besoin de protection prend souvent l'avant plan et les usagers se retrouvent surprotégés[9-13].

Malgré tout, les personnes ayant une DI veulent plus de connaissances en matière de sexualité[2,30], et le besoin d'obtenir du soutien chez ce groupe est incontestable[5-7].

Contexte

Le personnel de soutien dans les agences de services joue un rôle important dans la vie quotidienne d'adultes ayant une DI que ce soit dans les loisirs, les services en résidences, les services à l'emploi, ou même dans l'éducation. Ils augmentent les opportunités pour les personnes ayant une DI de vivre dans des environnements plus inclusifs[33] pour que ces derniers puissent jouir de relations réciproques, incluant les relations sexuelles[34]. D'ailleurs, les études ont démontré que le personnel de soutien influence directement la perspective que les personnes ayant une DI ont envers leur sexualité[27,36-37]. Par exemple, les attitudes du personnel envers la sexualité des personnes ayant une DI, découlant de leurs valeurs, croyances et expériences, peuvent mener à l'omission de discuter certains sujets avec les usagers comme la masturbation, diverses pratiques sexuelles, ou l'homosexualité[26]. Par ailleurs, certains membres du personnel de soutien ne se sentent pas à l'aise de discuter de la sexualité[5,38,39], ce qui peut mener à un manque d'éducation sexuelle et d'occasions pour les usagers de vivre une sexualité épanouie[40-42]. Finalement, le personnel de soutien rapporte un manque de confiance envers leurs habiletés à soutenir la sexualité et les relations des personnes ayant une DI[9]. Cela peut être le produit d'un manque de formation et de ressources disponibles aux membres du personnel afin qu'ils puissent soutenir la sexualité des adultes ayant une DI[27,36,43]. Le personnel de soutien a non seulement un besoin de formation, mais un besoin en lien avec les procédures de supervision et organisationnelles[44] et avec des politiques claires sur comment soutenir la sexualité des adultes ayant une DI[26].

Il existe des stratégies qui pourraient être mises en œuvre dans les agences de services afin de réduire les obstacles à la sexualité des adultes ayant une DI dont l'augmentation des réseaux de soutien, sensibiliser les aidants à l'impact qu'ils ont sur la sexualité des adultes ayant une DI, et l'éducation sur la sexualité et les relations sexuelles[5]. Bien que ces stratégies existent, et quelques-unes seront présentées dans ce résumé de preuves, elles ne sont pas utilisées actuellement par les agences de services. Selon le personnel de soutien ainsi que les adultes ayant une DI, plusieurs pratiques et politiques organisationnelles limitent les possibilités d'offrir des opportunités de soutenir la sexualité des adultes ayant une DI. Ceci dit, une approche de transfert de connaissances, incluant tous les membres concernés par cette problématique, est clé afin de synthétiser et mobiliser les connaissances en pratique et améliorer le soutien envers la sexualité des personnes ayant une DI.

Bien qu'il y ait des opinions divergentes sur comment aborder le sujet de la sexualité dans les agences de services, il existe tout de même un point en commun entre les membres du personnel : ***la sexualité est importante pour les adultes ayant une DI et le personnel veut être mieux équipé afin de soutenir la sexualité des adultes ayant une DI[36,45].***

Messages clés dans la présentation du problème :

- La sexualité est un droit fondamental pour les adultes ayant une DI
- Il existe plusieurs obstacles au soutien à la sexualité des adultes ayant une DI : haut taux d'agression sexuelle, faibles connaissances et expériences par rapport à la sexualité, manque d'éducation sexuelle, et peu de formation du personnel
- Le transfert des connaissances à la pratique est clé afin d'améliorer le soutien à la sexualité des personnes ayant une DI

Stratégies pour soutenir la sexualité des adultes ayant une déficience intellectuelle

Une recension des écrits a permis d'identifier 5 stratégies prometteuses pour soutenir la sexualité des adultes ayant une DI. Ces stratégies varient en termes de coûts, de ressources, et d'implications pour la mise en œuvre. Elles sont aussi soutenues par des niveaux de preuves variables. Le niveau de preuves est basé sur la qualité de l'étude en question, le type d'étude qui évalue la stratégie, et des biais potentiels associés à chaque type d'étude (University of York & NHS Centre for Reviews and Dissemination, 2009). Par exemple, les études ayant le plus haut niveau de preuves (3) sont des essais contrôlés avec répartition aléatoire. Dans ce type d'étude, le risque que les résultats soient influencés par des variables autre que la stratégie est minimale en comparaison à une étude observationnelle sans groupe contrôle. Ces stratégies incluent :

#1. La méthode *Nominal Group Technique* permet aux personnes ayant une déficience intellectuelle de discuter de sujets tabou comme la sexualité, identifier des thèmes clés et prioriser les thèmes;

#2 et 3. Deux programmes d'éducation sexuelle visant à augmenter les connaissances et les émotions positives pour les hommes ayant une DI;

#4. Un programme d'éducation sexuelle visant à augmenter les connaissances factuelles et les attitudes, croyances, et opinions envers la sexualité des adultes ayant une DI; et

#5. Un programme d'éducation sexuelle sur les relations respectueuses impliquant l'enseignement par les pairs.

Vous trouverez une description détaillée des stratégies à l'annexe 1 (tableau 1 à 4).

Stratégie 1 : Nominal Group Technique (NGT)

Niveau de preuve: 2

Le *Nominal Group Technique* (NGT) est utilisé pour explorer comment les personnes ayant une DI définissent et vivent leur sexualité dans le contexte de leur identité en tant que défenseurs de leurs droits. NGT, une méthode de recherche-action participative, est composée de discussions non-critiques, structurées et simples à comprendre pour les personnes ayant une DI. Des activités ont eu lieu avant le NGT (par exemple : jeux de rôles sur les relations, la sécurité et la présentation des droits liés à la sexualité pour les personnes ayant une DI) afin de familiariser les participants aux questions du NGT.

Étapes du *Nominal Group Technique* :

7. Donner une question ou un sujet aux participants et du temps de réflexion;
8. Demander aux participants d'écrire leurs réponses sur un papier;
9. Demander aux participants de partager leurs idées, un à la fois et une idée à la fois;
10. Prendre en note les idées sur un tableau et combiner les idées similaires sous des thèmes;
11. Discuter les thèmes avec le groupe, restructurer et valider les thèmes; et
12. Voter sur les thèmes pour donner un ordre de priorité.

Résultats clés :

- Les thèmes ressortis liés à la défense des droits par rapport à la sexualité incluent : se connaître et se respecter, respecter les autres, faire ses propres choix, parler pour soi-même, respecter leurs droits, avoir de l'information, et avoir des relations santé.
- Facilitateurs liés à la défense des droits par rapport à la sexualité: accroître l'accès à l'information et aux services de santé sexuelle, enlever les obstacles systémiques, éduquer les autres, augmenter l'accès au counseling, et développer des opportunités pour l'expression sexuelle.

Vos commentaires :

Stratégie 2 et 3 : Deux programmes d'éducation sexuelle

Niveau de preuve: 2.5

Cette étude présente deux programmes d'éducation sexuelle visant à augmenter les connaissances et émotions positives des hommes ayant une DI envers la sexualité. Les connaissances des participants ont été mesurées avant et après les programmes d'éducation sexuelle.

Stratégie 2 − Co-Care : 10 sessions hebdomadaires, 2h chacune avec 2 instructeurs (un de chaque sexe). Sujets couverts par le programme: émotions, langage corporel, habiletés sociales, cycle de la vie humaine, puberté, conscience du corps, comportement privé et publique, relations sexuelles, la conception, grossesses et accouchement, contraception (et ITSS), menstruation et comportement de protection

Résultats clés:

- Il y a eu une **augmentation significative des connaissances** par rapport à l'amitié, le mariage, les relations sexuelles, la contraception, la grossesse et l'homosexualité. Il y a eu une faible augmentation des connaissances sur l'identification des parties du corps, les ITSS et les interactions sexuelles.
- Il y a eu **plus d'émotions positives** suite au programme au sujet des amitiés avec les femmes et caresser quelqu'un du sexe opposé.

Stratégie 3 − Family Planning Victoria (FPV) : 6 sessions hebdomadaires, 1h chacune avec 1 instructeur. Sujets couverts par le programme: conscience de soi, émotions, conscience du corps, comportements privés et publiques, relations sexuelles, contraception, amitié et relations, SIDA et comportement de protection

Résultats clés :

- Il y a eu une **augmentation significative des connaissances** par rapport aux relations sexuelles, la contraception, la grossesse et les ITSS.
- Il y a eu **plus d'émotions positives** suite au programme au sujet des amitiés avec les femmes et caresser quelqu'un du sexe opposé.

Vos commentaires :

Stratégie 4 : Éducation sexuelle pour les adultes ayant une DI

Niveau de preuve: 2

Cette étude présente un programme d'éducation sexuelle visant à augmenter les connaissances sexuelles d'adultes ayant une DI dans des services résidentiels. Ce programme de six sessions, durant 2h30 à 3h chacune, inclut un curriculum, des diagrammes, des documents, des vidéos, et des tests. Les documents incluent des informations sur les infections transmises sexuellement et par le sang et les méthodes de contraception. Les diagrammes présentent l'anatomie des organes reproductifs masculins et féminins, le cycle menstruel, *Circle Concept* qui une méthode qui permet d'identifier les personnes qui entourent l'individu avec une DI selon leur niveau de familiarité, et une feuille de *Planned Parenthood* présentant différentes méthodes contraceptives. Des modèles de condoms et d'organes reproductifs *Jackson* sont aussi utilisés. Une méthode pré et post test a été utilisée afin de démontrer si le programme augmente les connaissances sexuelles et change les attitudes des personnes ayant une DI.

Résultats clés :

- Les connaissances factuelles sur la sexualité des adultes ayant une DI ont augmenté significativement après la participation au programme d'éducation sexuelle.
- Les connaissances subjectives liées aux attitudes, valeurs, croyances et opinions envers sa propre sexualité ont augmenté significativement après la participation au programme d'éducation sexuelle.
- Le programme a été très bien reçu par les participants. Le sujet de la sexualité était une grande motivation à participer au programme. Il n'y a pas eu d'autres incitations à la participation autre que le sujet. Par exemple, dû à des difficultés à organiser les activités dans l'agence de service, les participants manquaient souvent des activités sociales et des loisirs afin de participer aux sessions du programme.

Vos commentaires :

Stratégie 5 : Éducation sexuelle donnée par les pairs

Niveau de preuve: 1.5

Cette étude présente un programme d'éducation sexuelle, *Living Safer Sexual Lives : Respectful Relationship* (LSSL: RR), développé à partir du ancien programme *Living Safer Sexual Lives*, où le co-facilitateur du programme est un adulte ayant une DI. Ce programme a été développé à partir de 25 histoires de vie d'adultes ayant une DI obtenues durant multiples consultations avec chaque personne. 4 sessions: 1. Parler de la sexualité et des relations sexuelles, 2. Avoir des droits et être en sécurité, 3. Relations respectueuses, et 4. Les hommes et les relations respectueuses. Chaque session permet aux participants de faire des activités et de réfléchir sur de thèmes clés dont les droits dans une relation, l'intimité et les forces de chacun. Les participants sont encouragés de choisir un partenaire dans l'apprentissage dans leur cercle de soutien. Ce partenaire a le rôle de soutenir l'apprentissage de l'adulte ayant une DI dans le programme et apprend à la fois comment soutenir l'adulte pour qu'il ait des relations respectueuses. Le programme vise aussi l'engagement communautaire en formant des membres du personnel d'agences de service comme co-facilitateurs.

Résultats clés :

- Dans un projet pilote à court-terme du LSSL, les participants ont déclaré qu'il y avait une augmentation de leurs connaissances par rapport à leurs droits dans des relations, au sujet des services, au sujet des ressources disponibles pour les soutenir dans des relations, et au niveau de la confiance à parler du sujet de relations intimes avec les autres et d'offrir du soutien.
- Les pairs qui co-facilitaient le programme ont rapporté que l'éducation donnée par les pairs offrait un sentiment d'autonomisation, ont aidé à soutenir les autres, se sentait plus crédible que des professionnels, et a créé des opportunités d'apprendre de nouvelles choses sur les relations respectueuses, les ressources communautaires et des nouvelles habiletés.

Vos commentaires :

Conseils généraux pour la mise en œuvre

Quel que soit votre décision dans la sélection d'une ou d'une combinaison de stratégies à l'AISO, il y a plusieurs conseils dont il faut se rappeler. Ces conseils découlent d'une recension d'écrits scientifiques sur la sexualité et la déficience intellectuelle.

Il est aussi important de considérer les aspects clés à la livraison de programmes d'éducation sexuelle, étant donné que la majorité des stratégies identifiées pour ce résumé de preuves sont des programmes d'éducation sexuelle.

Formation du personnel et des aidants

Plusieurs conseils ont été identifiés par rapport à la formation du personnel de soutien :

- Le personnel a un besoin de formation et de ressources[27,36,43]
- Il existe un besoin de procédures organisationnelles et de politiques clairs[26,44]
- Dans les services où les procédures et politiques existent, le personnel rapporte un manque de formation afin que celles-ci soient mises en pratique[44]

Programmes d'éducation sexuelle

Bien que plusieurs outils, formations et programmes d'éducation sexuelle existent pour soutenir la sexualité des adultes ayant une DI, il y a plusieurs considérations à prendre en compte dans la mise en œuvre de ces programmes :

- L'éducation sexuelle pour les personnes ayant une DI se concentre souvent sur la prévention de conséquences négatives de la sexualité telles que la prévention d'agressions sexuelles, de grossesses non désirées, et d'infections transmises sexuellement et par le sang[24,25]
- L'emphase sur les aspects négatifs de la sexualité entrave le développement d'une attitude positive envers la sexualité[6]
- L'association entre la peur de risques et les expériences sexuelles peut nuire au développement de l'identité et de relations sexuelles pour les adultes ayant une DI[5,26,27]
- L'éducation sexuelle pour les personnes ayant une DI renforce une sexualité appropriée comme étant non-reproductive, solitaire, et hétérosexuelle[28,29]
- L'omission d'autres pratiques et orientations sexuelles dans les programmes peut empêcher l'exploration et la satisfaction sexuelle des personnes ayant une DI[27]
- L'enseignement par les pairs est une méthode qui permet d'adresser les besoins sexuels et reproductifs[53]
- L'éducation sexuelle doit se concentrer non seulement sur les connaissances mais aussi sur les habiletés et comment ses habiletés peuvent être généralisées à des situations de vie réelles[55]
- La majorité des programmes d'éducation sexuelle ont peu de base théorique et empirique et n'ont pas été sujet à une évaluation appropriée[25,54]
- Les stratégies incluses dans ce résumé de preuves ont toutes été sujet à l'évaluation et le niveau de preuve est un indice de la qualité des stratégies.

Favoriser l'autonomie des personnes ayant une DI

En plus des stratégies et conseils présentés vis-à-vis la formation et l'éducation sexuelle, il faut aussi penser à comment ces soutiens sont offerts aux personnes ayant une DI :

- Les personnes ayant une DI n'ont peut-être pas accès aux différentes sources d'informations et/ou ne comprennent pas le contenu[44]
- Les personnes ayant une DI dépendent souvent du personnel de soutien et des aidants afin d'identifier et répondre aux besoins sexuels[44]
- Il existe un besoin de favoriser l'autonomiser de la personne pour qu'elle puisse solliciter du soutien envers sa sexualité[44]
- Durant la planification centrée sur la personne (p.ex. choix d'un programme de jour), il est important que le personnel ou les aidants soulèvent la question de la sexualité[44]

Prise de risques

Les personnes ayant une DI ont une vulnérabilité accrue[18,19]. Ceci dit, il est difficile pour le personnel de soutien et les aidants de contrebalancer les droits des personnes ayant une DI à vivre une sexualité avec leur devoir de protéger les usagers contre les agressions[20-23]. Cependant, il y a quelques aspects clés à prendre en compte :

- Les stratégies de protection (p.ex. limiter les activités et le temps privé) ne sont pas suffisantes afin d'empêcher les agressions sexuelles[44]
- Les personnes ayant une DI ont besoin d'apprendre comment se protéger elles-mêmes[44]
- Il faut mettre l'accent sur la prise de risque positif[44] ce qui implique identifier les risques et développer un plan d'action qui reflète les aspects positifs potentiels et les priorités de la personne ayant une DI[56]

Obstacles et solutions potentielles

En choisissant une combinaison de stratégies à mettre en œuvre à l'AISO, il faut anticiper les obstacles potentiels, et de possibles solutions. En plus des avantages et limites présentés pour chaque stratégie, il est important de réfléchir aux autres facteurs qui pourraient avoir une influence sur le succès de la mise en œuvre à l'AISO. Ces facteurs sont présentés à la page suivante ainsi que les modifications potentielles à apporter aux stratégies. Cette liste de facteurs est une adaptation des critères pour la création d'un résumé de preuves par *The SURE Collaboration* (2011).

Tableau 5. Obstacles et solutions potentielles à la mise en œuvre

Personnes recevant un service	
Obstacles	***Solutions***
Connaissances et habiletés Il est possible que la stratégie en question ne réponde pas aux besoins des personnes ayant une DI ou qu'elle soit pour des personnes ayant différents niveaux de soutien.	Vérifier s'il est possible de modifier la stratégie afin qu'elle soit mieux alignée avec les besoins des personnes recevant un service. Avant de faire une modification quelconque, il serait important d'en discuter avec les personnes ayant une DI.
Attitudes envers la stratégie Il est fort probable que les personnes recevant les services de l'AISO ainsi que leurs aidants aient des opinions et expériences uniques.	Il est important de consulter les personnes recevant les services et leurs aidants pour toute modification aux stratégies et d'être transparent dans les raisons pour lesquelles une stratégie n'a pas été possible (ex : manque de ressources).
Motivation Il peut y avoir une certaine résistance des personnes recevant un service de l'AISO et de leurs aidants vis-à-vis la participation dans ce projet étant donné la nature tabou du sujet de la sexualité et des attitudes négatives envers celle-ci.	Étant donné l'intérêt envers les groupes de discussions sur la sexualité, la participation à la mise en œuvre risque de ne pas être un problème. Si jamais les personnes recevant un service et leurs aidants refusent de participer, il serait important d'explorer pourquoi.
Personnel de soutien	
Obstacles	***Solutions***
Connaissances et habiletés Le personnel de l'AISO a diverses connaissances et habiletés dans le soutien envers la sexualité des personnes recevant un service et des stratégies dans ce résumé de preuves. Il est aussi possible que ceux-ci n'aient pas les habiletés pour mettre en œuvre la stratégie.	Il sera important de recruter des membres du personnel de soutien qui ont les connaissances ou habiletés nécessaires pour la mise en œuvre. Si cela n'est pas possible, il faut alors recruter des membres qui sont motivés à recevoir la formation nécessaire.

Attitudes envers la stratégie Le personnel de l'AISO va surement avoir des attitudes et opinions différentes envers les stratégies dans le résumé de preuves.	Il est important que ceux-ci partagent leurs opinions durant le dialogue avec les parties prenantes et que l'on discute des désaccords.
Motivation Le personnel de l'AISO va surement avoir des niveaux de motivation différents envers la mise en œuvre des stratégies.	Il est important de recruter les membres du personnel de soutien qui sont les plus motivés à participer afin de favoriser le succès de la mise en œuvre de la stratégie. Il faut tenir compte de la disponibilité du personnel dans la sélection de la stratégie puisque cela va influencer la motivation.
Limites organisationnelles	
Obstacles	***Solutions***
Ressources financières Il est possible que l'AISO n'ait pas les ressources financières nécessaires pour la mise en œuvre d'une stratégie.	La stratégie ou la combinaison de stratégies peut être modifiée afin de réduire les coûts.
Ressources humaines Il est possible que l'AISO n'ait pas le personnel nécessaire pour mettre en œuvre la stratégie ou que celui-ci ne soit pas disponible.	L'AISO pourrait considérer d'obtenir du soutien de personnes externes ou de bénévoles pour la mise en œuvre et envisager des partenariats avec des ressources dans la communauté (ex : Planned Parenthood, Centre d'aide et de lutte contre les agressions à caractère sexuel (CALACS)).
Prise de décisions Il se peut que durant la mise en œuvre, ceux impliqués doivent prendre des décisions qui vont au-delà de leurs rôles (ex : changement de politique organisationnelle).	Le comité consultatif sera consulté pour la prise de décision durant la mise en œuvre de la stratégie et, au besoin, la direction.
Règlements Il se peut que des politiques internes empêchent la mise en œuvre de la stratégie.	Le comité consultatif sera consulté et l'AISO devra prendre en considération la modification des politiques ou la création d'une nouvelle politique. Il est aussi possible de modifier la stratégie pour qu'elle soit en lien avec les politiques de l'AISO.

Résumé des consultations

Des consultations ont eu lieu avec différentes parties prenantes à l'AISO (personnes recevant un service, les aidants et les membres du personnel). Ces consultations avait pour objectif d'explorer comment les gens perçoivent le soutien qu'ils reçoivent de l'AISO dans le développement et le maintien d'une sexualité épanouie. Nous avons discuté des soutiens couramment offerts, des obstacles, des recommandations et des stratégies identifiées dans la littérature scientifique qui pourraient être mise en œuvre à l'AISO pour mieux soutenir la sexualité des personnes recevant un service. Les consultations étaient divisées par groupe selon la dimension de la sexualité. **Le groupe A (sexualité individuelle)** portait sur des sujets de base reliés à la sexualité : par exemple, l'identité sexuelle, la masturbation, ou le consentement. **Le groupe B** (**sexualité relationnelle**) portait sur des sujets plus avancés : par exemple, la communication sexuelle, des pratiques sexuelles sans risques, ou avoir un enfant.

Au total, il y a eu :

- deux groupes de 4-6 personnes recevant un service qui se sont rencontrées à trois différentes occasions;
- deux groupes de 2-10 aidants (parents et personnes ressources) se sont rencontrées une fois; et
- deux groupes de 10-15 membres du personnel (conseillers) se sont rencontrées une fois.

Personnes recevant les services

Soutien offert : Les personnes recevant un service rapportent que l'AISO joue un rôle important dans leur vie quotidienne. En terme du soutien offert à l'AISO envers la sexualité des personnes recevant les services, l'AISO organise plusieurs activités pour rencontrer des gens tels que les danses, le quilles-thon, des soirées cinéma, des barbecues, et la piscine. Ils rapportent une très bonne communication avec le personnel de l'AISO. Aucune personne rapporte avoir reçu de l'éducation sexuelle à l'AISO. Celle-ci est surtout donnée par la famille ou par l'école.

Obstacles : Les personnes recevant un service rapportent un manque de temps privé. Ils ont discuté des limites à l'intervention du personnel, par exemple à naviguer le système de l'aide à l'enfance.

Recommandations : Les personnes recevant un service aimerait des ateliers ou un programme d'éducation sexuelle pour apprendre au sujet de la sexualité. Le contenu et le format d'apprentissage dépend de la personne. Certains préfèrent apprendre au sujet des différences entre les sexes, la puberté, la contraception, la grossesse, comment avoir des relations sexuelles et diverses pratiques sexuelles. D'autres personnes recevant un service aimerait de l'éducation sexuelle qui va plus en profondeur, par exemple, prendre soin d'un enfant et les émotions liées à la sexualité. Certains préfèrent du un-à-un tandis que d'autres aimeraient apprendre et discuter au sujet de la sexualité en groupe. Ils sont tous d'accord que des aides visuelles seraient utiles. Ils préfèrent de vraies images que des dessins.

Stratégies : Ils ont une préférence pour la stratégie #5, l'éducation sexuelle donnée par les pairs, à cause de la familiarité et la crédibilité accrue d'avoir un pair comme instructeur. Il y a eu beaucoup d'intérêt envers être l'instructeur du programme. La deuxième stratégie choisie était la technique de groupe nominale (NGT) (stratégie #1). Ils rapportent que ces groupes de discussion seraient utiles mais que les sujets couverts et les personnes dans le groupe peuvent variés. Par exemple, il pourrait y avoir des groupes seulement pour les femmes. En général, ils aimeraient un mélange des stratégies, que le contenu, la durée et le format soient adaptés selon la personne (ses intérêts, connaissances et expériences), et que la stratégie soit interactive avec des jeux ou des activités en plus de la discussion.

Aidants

Soutien offert : Les aidants rapportent beaucoup d'humanité, de soutien et de motivation à l'AISO. Lorsqu'ils ont une question, l'AISO trouve la solution pour les aidants. Cependant, il faut faire la demande afin de recevoir les ressources et d'avoir accès aux services à l'extérieur. En plus des activités mentionnées par les personnes recevant un service, les aidants rapportent aussi des ateliers offerts par le Mouvement personne d'abord. Il n'y a pas de programme d'éducation sexuelle mais ils utilisent parfois les cercles de soutien dans l'intervention. Les aidants rapportent que le personnel donne l'éducation sexuelle à la personne quand il y a un besoin d'intervenir.

Obstacles : Au meilleur de leurs connaissances, il ne semble pas y avoir de politique, de règlement, ou de consensus sur comment soutenir la sexualité des personnes. Les aidants rapportent que le soutien offert envers la sexualité dépend des attitudes, croyances, et valeurs du personnel qui offre ce soutien.

Recommandations : Les aidants aimeraient être plus impliqués. Ils aimeraient avoir plus de ressources vis-à-vis la sexualité (p.ex. un carnet de ressources avec les questions communes), une formation et une plus grande communication entre eux et l'AISO. Ils aimeraient aussi plus d'atelier du Mouvement et d'activités organisées pour les personnes afin qu'ils puissent développer des amitiés et que celles-ci ne soient pas seulement des danses. Ils rapportent que les foules et les bruits durant la danse posent problèmes pour certaines personnes. Ils aimeraient aussi qu'il y ait un(e) spécialiste en sexualité qui puisse rencontrer les personnes indépendamment du personnel et des aidants pour répondre aux questions de natures sexuels. Les aidants aimeraient être impliqués plus tard dans le processus et pouvoir contacter cette personne au besoin.

Stratégies : Les aidants ont une préférence pour un mélange entre la stratégie #1, le NGT, et la stratégie #5, l'éducation sexuelle donnée par les pairs. Ils aimeraient qu'un expert en sexualité soutien la personne recevant un service qui donne l'éducation sexuelle ou mène les groupes de discussion. Il y a des craintes que la stratégie #4 soit trop abstraite pour certains qui ne savent pas écrire et renforce le besoin d'utiliser des aides visuels. Finalement, ils proposent qu'impliquer le Mouvement personne d'abord pour aider à la mise en œuvre des stratégies.

Personnel de soutien

Soutien offert : Un programme d'éducation sexuelle existe à l'AISO : la sexo-trousse. Cependant, ce programme est très ancien et est rarement utilisé aujourd'hui. Les cercles de

soutien sont utilisés au besoin. Parfois l'AISO cherche des services à l'extérieur (ex : service catholique des interventions sexuelles). Le personnel ne rapporte pas avoir eu de formation en matière de la sexualité sauf envers les agressions sexuelles menée par CALACS. Ils travaillent avec leurs connaissances personnelles. En termes de politiques ou de règlements, il n'y a rien au sujet de la sexualité sauf des politiques de l'agence envers l'abus en général. Les activités sont les mêmes que mentionnés dans les autres groupes. Certaines activités sont organisées strictement par l'AISO, d'autres par le Mouvement personne d'abord avec le soutien de l'AISO.

Obstacles : Tel que mentionné par les aidants, le personnel rapporte que la sexualité de la personne va s'exprimer différemment selon le personnel qui travaille ce jour-là (par exemple, ce qui est acceptable ou non comme comportement sexuel). D'autres rapportent que le personnel n'est pas un obstacle. Il existe une incohérence dans l'intervention du personnel envers la sexualité de la personne recevant un service. Le personnel n'intervient pas à moins que la personne souhaite du soutien envers sa sexualité ou qu'il y ait des comportements qui nécessitent une intervention du personnel.

Recommandations : Le personnel aimerait une formation sur la sexualité autant pour les personnes recevant un service que pour le personnel. Ils aimeraient que les deux soient impliqués. Ils soulignent l'importance d'un programme d'éducation sexuelle adapté à la personne et utilisant des aides visuelles.

Stratégies : Le choix de la stratégie et le contenu va varier selon les personnes qui y participent. Pour certains les notions de bases sont importantes (ex : contraception, différences entre les corps); pour d'autres, il faut aller au-delà (ex : relations interpersonnelles et la communication). Ils ont une préférence envers la stratégie #1, le NGT, et la stratégie #5, l'enseignement par les pairs. Selon le personnel, le NGT crée l'opportunité pour la personne de dire ce qui est important pour elle et de prioriser. Ils aiment l'idée de pouvoir parler avec les personnes mais que ce soit la personne qui prend les décisions par rapport à sa sexualité. Au niveau de la stratégie #5, le personnel rapporte que le programme va au-delà des notions de base en sexualité et implique les personnes qui reçoivent un service ce qui est directement en lien avec le mandat de l'AISO. En bref, un mélange des deux programmes serait bien. Ils rapportent l'importance d'évaluer les besoins de la personne, de rendre le tout court et visuel, et de faire de plus petits groupes, au besoin.

Prochaines étapes

Ce résumé de preuve vise à favoriser une discussion et des jugements informés par les meilleures preuves disponibles en préparation pour une rencontre avec les membres du personnel, l'équipe de gestion, les usagers, et les aidants. La rencontre aura lieu le 30 novembre à partir de 12h au siège social de l'AISO. Ce document ne vise pas à promouvoir une stratégie en particulier ou clore la discussion sur comment soutenir la sexualité des adultes ayant une DI. Les prochaines étapes sont de discuter du résumé de preuves. Ces discussions peuvent porter sur :

- Une combinaison de stratégies pour mieux soutenir la sexualité des usagers.
- Modifier, élargir, ou sélectionner des éléments d'une stratégie afin de mieux répondre aux besoins et aux ressources disponibles à l'AISO (ex : disponibilité du personnel et des usagers, coûts, locaux, durée).

- Créer une nouvelle stratégie à partir des informations dans le résumé de preuves, des consultations et des discussions durant le dialogue entre parties prenantes (ex : le développement d'une politique organisationnelle ou une formation du personnel).

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Annexe 1 : Résumé détaillé des stratégies

Tableau 1: Étude sur le *Nominal Group Technique* (NGT) (stratégie 1)

Sources : Friedman, C., Arnold, C. K., Owen, A., et Sandman, L. (2014). "Remember our voices are our tools:" Sexual self-advocacy as defined by people with intellectual and developmental disabilities, *Sexuality and Disability*, 32, 515-532.

Owen, A., Arnold, K., Friedman, C., et Sandman, L. (2016). Nominal Group Technique: An accessible method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities, *Qualitative Social Work*, 15(*2*), 175-189

Participants: 35 adultes ayant une DI
Lieu: Chicago, États-Unis, durant une journée au Community Research Forum
Intervention: Participation à un groupe de discussion NGT
Comparaison: Aucune
Niveau de preuve : 2

Résultats	• Thèmes clés : se connaître et se respecter, respecter les autres, faire ses propres choix, parler pour soi-même, respecter leurs droits, avoir de l'information, avoir des relations santé. • Facilitateurs : accroître l'accès à l'information et aux services de santé sexuelle, enlever les obstacles systémiques, éduquer les autres, augmenter l'accès au counseling, et développer des opportunités pour l'expression sexuelle
Avantages	• Études ont utilisé NGT pour discuter de sujets complexes, difficiles et tabous • Donne un espace pour que les personnes ayant une DI partagent leurs opinions et expériences • Personnel peut utiliser NGT pour incorporer les idées des usagers sur la sécurité, la vie privée, et les relations sexuelle • Peu dispendieux et courte durée
Limites	• Groupe trop large (n = 35), idéalement NGT est fait avec 5-9 participants • Difficile à faire avec ceux qui ont de plus grands besoins de soutien ou qui sont non-verbaux

Tableau 2: Étude sur l'utilisation de deux différents programmes d'éducation sexuelle (stratégie 2 et 3)

Source : Garwood, M. et McCabe, M. P. (2000). Impact of sex education programs on sexual knowledge and feelings of men with mild intellectual disability, *Education and Training in Mental Retardation and Developmental Disabilities,* 35(*3*), 269-283.
Participants: 6 hommes (3 pour le Co-Care, 3 pour le FPV),
Co-Care entre 12 et 25 ans (Moyenne = 19), FPV entre 28 et 32 ans (Moyenne = 31.6)
Lieu: Australie
Intervention: Deux programmes d'éducation sexuelle : Co-Care et FPV
Comparaison: Comparaison entre mesures pré et post intervention utilisant le Sex Ken-ID
Niveau de preuve : 2.5

Résultats	• Augmentation minimale des connaissances des participants dans chaque programme dans la majorité des sujets du Sex Ken-ID
	  ○ Augmentation moyenne du groupe Co-Care sur : l'amitié, le mariage, le sexe, la contraception, et l'homosexualité
	  ○ Augmentation moyenne du groupe FPV sur : le sexe, la grossesse et l'accouchement, et les infections transmises sexuellement et par le sang
	• Augmentation des émotions positives dans les deux groupes envers l'amitié avec les femmes et caresser quelqu'un de l'autre sexe

Avantages	• Participants ont beaucoup de fausses croyances par rapport à la sexualité (ex : si on embrasse quelqu'un = on va avoir une infection transmise sexuellement et par le sang), dont l'importance de l'éducation sexuelle
Limites	• Peu de participants dans chaque programme donc impossible de comparer quantitativement les scores pré et post-test du Sex Ken-ID • Ceux qui n'avaient pas de connaissances sur un sujet (ex : homosexualité) ne pouvait pas répondre aux questions d'émotions sur le même sujet

Tableau 3: Étude sur l'utilisation d'un programme d'éducation sexuelle (stratégie 4)

Source : Caspar, L. A. et Glidden, L. M. (2001). Sexuality Education for Adults with Developmental Disabilities, *Education and Training in Mental Retardation and Developmental Disabilities*, 36 (*2*), 172-177

Participants: 12 adultes (9 femmes, 3 hommes), entre 28 et 62 ans (Moyenne = 38.7)
Lieu: Melwood, États-Unis, une agence de service communautaire offrant des services résidentiels et formation professionnelle
Intervention: Programme d'éducation sexuelle + documents + diagrammes + vidéos + modèles anatomiques
Comparaison: Dans la livraison des tests A et B pour le pré et post intervention
Niveau de preuve : 2

Résultats	• Différence significative entre pré et post test dans les connaissances factuelles • Différence significative entre pré et post test dans les informations subjectives telles que les attitudes, opinions et valeurs envers sa sexualité • Anecdotes que le programme a augmenté les occasions d'apprentissages, qu'il y a eu de la discussion entre les participants sur le matériel et des demandes pour plus d'informations et d'aide avec les problèmes liés à la sexualité
Avantages	• Augmente les connaissances, améliore les attitudes et sensibilise les adultes ayant une DI à la sexualité • Résultats obtenus dans un contexte typique d'agences de services avec les contraintes de temps et du personnel suggère qu'il peut être reproduit dans d'autres contextes similaires • Programme court et intensif donné dans des salles de classes • Non dispendieux • Disponible au public ou on peut le recréer • Valeur du programme reconnue par les participants
Limites	• Participants recrutés non aléatoires et non représentatifs de la population (échantillon de commodité) o Participants avaient majoritairement déjà eu des comportements sexuels inappropriés • Problèmes avec les réactions affectives des participants qui perturbent la présentation du matériel et crée de la confusion o Besoin d'un assistant afin de gérer les distractions • Le rôle de l'instructeur o Instructeur facilite aussi des services psychiatriques, psychothérapeutiques, comportementaux et de gestion de crises o Besoin de plus de sessions en parallèle avec moins de participants

Tableau 4: Étude sur l'éducation sexuelle donnée par les pairs (stratégie 5)

Source: Frawley, P. & Bigby, C. (2014). 'I'm in their shoes': Experiences of peer educators in sexuality and relationship education, *Journal of Intellectual and Developmental Disabilities*, 39(*2*), 167-176.

Participants: 16 adultes ayant une DI
Lieu: Australie
Intervention: Utilisation de l'enseignement par les pairs
Comparaison: Aucune
Niveau de preuve : 1.5

Résultats	• Dans un projet pilote à court-terme du LSSL (LSSL: ID) les participants ont déclaré qu'il y avait augmentation de leurs connaissances par rapport à leurs droits dans des relations, au sujet des services, au sujet des ressources disponibles pour les soutenir dans des relations, et au niveau de la confiance à parler du sujet de relations intimes avec les autres et d'offrir du soutien • Ce programme a été développé à partir de 25 histoires de vie d'adultes ayant une DI obtenues durant multiples consultations avec chaque personne. • Les pairs qui co-facilitaient le programme ont rapporté que l'éducation donnée par les pairs offrait un sentiment d'autonomisation, ont aidé à soutenir les autres, se sentait plus crédible que des professionnels, et a créé des opportunités d'apprendre de nouvelles choses sur les relations respectueuses, les ressources communautaires et des nouvelles habiletés.
Avantages	• Crée un partenariat entre les adultes ayant une DI et les professionnels en communauté et renforce le lien entre ces adultes avec les défenseurs de leurs droits, et les services disponibles • Méthode participative et active pour les adultes ayant une DI • Enseignement par les pairs perçue et vécue comme étant bénéfique
Limites	• Faible nombre de participants donc les résultats ne sont pas généralisables • Notion de *Gatekeeping* où des professionnels d'agences de services ne soutiennent pas le modèle d'enseignement par les pairs à la base du programme (ex : irréaliste puisqu'ils ne sont pas dans des relations respectueuses, pas la capacité d'être des facilitateurs, etc.)

Appendix E: Pre-Structured Case Summary Outline for Stakeholder Dialogue

Pre-Structured Case Summary Outline

I. Overview of previous study findings
   a. Five scoping review strategies
   b. Focus groups

II. Identifying a strategy to implement within the agency
   a. Comparing and contrasting options
   b. Implementation considerations that are agency specific (e.g., time, resources, priorities)

III. Implementation team
   a. Decisions on the implementation team members (i.e., roles and responsibilities)
   b. Planned activities for the implementation (e.g., identifying the resources required, documentation, timelines)

Appendix F: Protocol for Half-Day Stakeholder Dialogue

Protocole pour dialogue entre parties prenantes d'une demi-journée

INFORMATION ADMINISTRATIVE

Détails:

- Durée: 4 heures
- Lieu: AISO, salle 205
- Rôles :
    - Virginie – modératrice
    - Natasha – présenter le projet et le résumé des consultations
    - Bénévoles
        - Organiser les enregistrements audios
        - Prise de notes
        - Aide avec les questionnaires

Matériels à préparer et amener:

- Général:
    - Présentation PowerPoint
    - Lettres d'invitation et formulaires de consentement (2 copies par participant)
    - Instructions pour la discussion avec parties prenantes ajouté au PowerPoint:
        - *Partagez vos pensées avec le groupe, si vous le voulez.*
        - *Parlez une personne à la fois.*
        - *Ne partagez pas l'information personnelle des gens dans le groupe aux gens à l'extérieur de ce groupe.*
    - 2 enregistreurs audio (iPads)
    - Café et collations pour les participants

PARTIE 1 : 12h – 13h

INTRODUCTION (Virginie, 5 min) 12h00-12h05, diapos

- Petit mot d'intro
- Présenter l'équipe et le rôle de chacun
    - Virginie – modératrice
    - Natasha – présenter le projet et les résumés des consultations
    - Danielle et Joyce – prise de notes

- Introduction des participants
    - Nom et rôle dans l'agence (personne recevant un service, aidants, personnel)
- **Objectif du dialogue** – nous allons choisir une stratégie pour soutenir la sexualité des membres de l'AISO. Nous allons travailler avec le personnel de l'AISO pour développer cette stratégie après cette discussion de groupe. Fait partie de la thèse de Natasha : Nous voulons savoir comment la recherche sur soutenir la sexualité est utilisée par l'AISO.
- Agenda
    - Présentation du projet et des résumés des consultations. Ensuite discussion en groupe sur le résumé des consultations/opportunité de poser des questions
    - Personnes recevant un service, les aidants et les membres de l'équipe de gestion vont remplir un formulaire sur leurs opinions vis-à-vis la rencontre. Important pour la thèse de Natasha
    - Ensuite, les personnes recevant un service, les aidants et les autres qui le souhaitent vont quitter la pièce. Les chercheurs et les autres participants vont continuer la rencontre et regarder si c'est possible de mettre en place une ou des stratégies pour soutenir la sexualité des personnes qui reçoivent les services de l'AISO.
    - Personnel va discuter de comment les changements auront lieu à l'AISO et choisir une équipe de mise en œuvre.
    - Aviser les gens qu'ils peuvent se déplacer au besoin ou aller aux toilettes.

PRÉSENTATION DU PROJET (Natasha, 5 min) 12h05-12h10, diapos

- Expliquer le projet : recherche sur le soutien envers la sexualité
    - CONTEXTE: agences de services joue un rôle important dans le soutien envers la sexualité (discuter du problème du résumé de preuve)
    - OBJECTIF: voulons savoir comment la recherche sur le soutien envers la sexualité est utilisée par l'AISO
    - MÉTHODE (7 étapes, montrer la figure):
        - Revue de la littérature sur les stratégies pour soutenir la sexualité
        - Consultations (expliquer but et sujet couvert)
            - Nous avons eu des consultations avec les personnes recevant un service, les aidants et le personnel de l'AISO
            - Nous avons discuté du soutien offert par l'AISO envers la sexualité
    - DÉMONTRER À QUOI SERT LE DIALOGUE DANS LE PROJET
        - Le but du dialogue est de discuter des résultats des consultations
        - Personnel va ensuite discuter des stratégies et décider ce qu'il est possible de faire à l'AISO

CONSENTEMENT (5 min) 12h10-12h15

- *Donner copie du consentement aux participants (devrait avoir reçue l'autre copie a priori)*

Points clés :

- La rencontre est enregistrée
- La participation est volontaire
- Vous avez le droit de quitter si vous le souhaitez
- *Répondre aux questions des participants*
    - *Obtenir le consentement écrit*

Natasha et Danielle vont être témoins du consentement des participants.

PRÉSENTATION DES STRATÉGIES et RÉSUMÉ DES CONSULTATIONS (Natasha, 15 min) 12h15-12h30:

- *Utiliser le résumé de preuve*
- Survol des stratégies
- Survol des consultations

DISCUSSION: STRATÉGIES et RÉSUMÉ DES CONSULTATIONS (Virginie – 20 min; 12h30-12h55)

- Parties prenantes auront la chance de poser des questions aux aidants, personnel et personnes recevant un service sur les consultations. Les questions pour le groupe seront :
    1. Avez-vous des questions ou besoin de clarification de la part des participants des consultations?
        - Que voulez-vous dire par X?
        - Avez-vous un exemple de X?
        - Pourquoi est-ce que X est important?
    2. Si les participants ont de nouvelles idées, que pensez-vous de ces idées?
    3. Quel est le degré d'implication que les personnes recevant un service et les aidants souhaitent avoir dans le reste du processus?

MOT DE FIN POUR PERSONNES RECEVANT SERVICE ET AIDANTS (Virginie - 5 min; 12h55-13h)

- Remercier les participants
- Clarifier que maintenant seulement les membres du personnel vont continuer la rencontre afin de discuter des stratégies et de la résolution des problèmes potentiels autour des stratégies pour la mise en œuvre à l'AISO.
- Durant la discussion, Natasha va s'assurer que l'opinion des personnes recevant un service et des aidants est prise en considération.
- Il est possible qu'aucune stratégie ne soit mise en œuvre. Il y a plusieurs étapes à la mise en œuvre d'un nouveau service, politique, etc. Ou cela peut prendre du temps.

- Demander aux personnes recevant un service et aux aidants de remplir le questionnaire.
- Demander au personnel de quitter la pièce pour une pause et revenir dans 15 minutes.
- Avant de quitter et que je passe les questionnaires, est-ce qu'il y a quelque chose que vous voulez partager avec le groupe? Avez-vous des questions?

Danielle va chercher les bénévoles

- *Bénévoles: Danielle et Joyce*

PAUSE/QUESTIONNAIRE (15 min, 13h-13h15)

- Nous avons des bénévoles prêts à vous aider à répondre au questionnaire, au besoin.
- Vos réponses sont privées.
- Nous voulons connaître vos opinions, autant positives que négatives, pour améliorer nos rencontres.
- *Personnes recevant un service et aidants vont compléter le questionnaire (bénévoles vont aider au besoin)*

PARTIE 2 (1h15 min, 13h15-15h20)

RÉSUMÉ DE PARTIE 1 (Virginie, 10 min, 13h15-13h25)

Personnel vont utiliser le résumé de preuves page 8 à 12 sur les stratégies. Il y aura un endroit pour écrire des notes et commentaires.

- Faire un survol de la partie 1 : Virginie va faire un sommaire des discussions sur les stratégies et des points clés sur ce qui est efficace et sur quoi les participants sont en accord.
    - Concentrer sur les stratégies qui ressortent des discussions à date.
    - Dire explicitement quelles sont les meilleures options pour les stratégies. Mentionner la combinaison de stratégies si celle-ci a été mentionnée par les participants antérieurement.
    - Importance sur ce que les personnes recevant un service souhaite et ne souhaite pas comme stratégie.

** Virginie va prendre des notes sur les points clés de la discussion sur une affiche comme rappel au groupe.*

DISCUSSION POUR CHOISIR UNE STRATÉGIE (Virginie – 1h; 13h25-14h25)

- Informer les participants qu'il faut maintenant prendre une décision sur une stratégie ou une combinaison de stratégies à mettre en œuvre.
- Comparer/contraster les meilleures options
    - Est-ce qu'une stratégie est meilleure que les autres?

        - Est-ce que cette stratégie sera bien reçue par les personnes recevant un service? *Penser aux besoins et désirs de chaque groupe.*
        - Le personnel?
        - Les aidants?
    - Est-ce qu'il y a une combinaison de stratégies qui semblerait meilleure?
    - Est-ce que cette stratégie est réaliste?
    - Quels sont les défis dans la mise en œuvre de cette stratégie?
    - Comment pouvez-vous surmonter ces défis?
- Suite à cette discussion, demander aux participants d'indiquer la stratégie de leur choix. S'il y a un désaccord, permettre aux participants d'en discuter et de résoudre les conflits. En fin de compte, la stratégie choisie sera la stratégie choisie par la majorité.
- Virginie va faire un sommaire de ce qui est dit « j'entends xyz… est-ce que j'ai bien compris? »

PAUSE (10 min; 14h25-14h35)

PARTIE 3 (14h35-16h)

DEVELOPPER UN PLAN DE TRAVAIL (Virginie – 1h; 14h35-15h35)

(Faire plan de travail sur projecteur et écrire directement dedans)

Important d'identifier les leaders et une date de rencontre

- Nous allons maintenant faire un plan pour la mise en œuvre de la stratégie à l'AISO
- Jusqu'à la fin avril, Natasha va vous rencontrer pour discuter du processus (ex: des échéanciers, des étapes du processus, des décisions prises, et de questions potentielles que vous avez) – pour comprendre comment l'agence utilise les données de recherche pour mettre en œuvre la stratégie.
- Que faut-il faire pour mettre en œuvre la stratégie? Quels sont les grandes lignes/étapes?
- Combien de membres faut-il dans l'équipe de mise en œuvre? Qui devrait la composer?
    - Est-ce qu'il y a des membres du personnel ici qui aimeraient participer?
        - *Si personne veut participer, travailler la résolution de problèmes pour comprendre pourquoi personne veut participer et comment recruter des participant. On peut aussi suggérer des bénévoles.*
        - *Si plusieurs sont intéressés, il faut discuter de qui serait le plus disponible, apte, le plus motivé, etc.*
    - Est-ce qu'il y a quelqu'un qui n'est pas ici aujourd'hui (personnel ou bénévole) qui devrait faire partie de l'équipe? Pourquoi?
        - *Discuter de comment consulter des personnes.*
- Quel va être le rôle de chacun dans l'équipe?

- Informer le groupe que Natasha va prendre contact avec eux en janvier pour organiser les rencontres aux deux semaines. Natasha va participer aux rencontres et aider avec la résolution de problèmes.

ÉVALUATION ET CONCLUSION (Virginie - 25 min; 15h40-16h)

- Remercier les participants.
- Demander aux participants de remplir le questionnaire sur l'utilisation du résumé de preuves et du dialogue avec parties prenantes comme méthode pour utiliser la recherche afin de choisir une stratégie pour soutenir la sexualité. Encourager les participants à laisser des commentaires.
- Avant de quitter- Est-ce qu'il y a des questions ou commentaires?

Appendix G: Process Evaluation Questionnaire for Agency Personnel

Numéro d'identification : _____ Date : _____

Section A –Informations contextuelles :

1. Âge: _____

2. Sexe:

   - ☐ Homme
   - ☐ Femme
   - ☐ Autre

3. Rôle:

   ☐ Direction/Gestion – Précisez le poste : _____
   - Services résidentiels
   - Soutien aux adultes
   - Participation communautaire
   - Soutien à l'emploi
   - Services de répit

   ☐ Personnel de soutien – Précisez le poste : _____
   - Services résidentiels
   - Soutien aux adultes
   - Participation communautaire
   - Soutien à l'emploi
   - Services de répit

4. Depuis comment longtemps occupez-vous ce poste :
   - ☐Moins de 2 ans
   - ☐ Entre 2 à 5 ans
   - ☐ Entre 5 et 10 ans
   - ☐ Plus de 10 ans

Section B –Méthode de distribution du résumé de preuves:

L'AISO a accepté de contribuer à un projet de recherche pour comprendre comment les connaissances découlant de la recherche au sujet du soutien à la sexualité des personnes ayant une déficience intellectuelle sont mises en pratique dans des agences de services communautaires. Dans le cadre de ce processus, un résumé de preuves a été distribué le *DATE*. Le résumé de preuves a présenté différentes stratégies pour soutenir la sexualité de personnes

ayant une déficience intellectuelle. Il décrit chaque stratégie ainsi que les avantages et difficultés associés à la mise en pratique de chaque stratégie.

5. Avez-vous reçu le résumé de preuves?
   - ☐ Oui
   - ☐ Non (Sauter à la Section D)

6. A) Comment avez-vous reçu le résumé de preuves?
   - ☐ Électroniquement
   - ☐ Par la poste
   - ☐ Version papier reçue en personne
   - ☐ Autre: _____

   B) Auriez-vous préféré recevoir le résumé de preuves autrement? Si oui, comment auriez-vous préféré le recevoir?

   _____
   _____

7. Qui vous a distribué le résumé de preuves?

   - ☐Chercheur
   - ☐Collègue
   - ☐Aidant d'un membre de l'AISO
   - ☐Membre de l'AISO
   - ☐Autre : _____

8. A) Quand avez-vous reçu le résumé de preuves?
   - ☐ 3 semaines avant la discussion avec parties prenantes
   - ☐ 2 semaines avant la discussion avec parties prenantes
   - ☐ 1 semaine avant la discussion avec parties prenantes
   - ☐ Moins qu'une semaine avant la discussion avec parties prenantes
   - ☐ Autre : _____

   B) Auriez-vous préféré recevoir le résumé de preuves à un autre moment? Si oui, quand auriez-vous préféré le recevoir?

   _____
   _____

9. Avez-vous lu le résumé de preuve?

   - ☐ Oui – Complètement lu le résumé de preuves (sauter à la question 10)

   - ☐ En partie – Lu des parties du résumé de preuves

Parties lues:

_____
_____
_____

□ Non – N'a pas lu le résumé de preuves

10. Pouvez-vous svp préciser pourquoi vous n'avez pas lu le résumé de preuves au complet? (Cocher toutes les cases pertinentes)

□ Résumé de preuves était trop long.
□ N'a pas eu assez de temps.
□ Résumé de preuves ne semblait pas pertinent/important.
□ Autres:

_____
_____
_____

11. Avez-vous utilisé l'information du résumé de preuve avant la discussion avec parties prenantes (la rencontre d'une demi-journée où nous avons discuté des stratégies dans le résumé de preuves, de la sélection d'une stratégie et d'une équipe pour la mise en pratique de la stratégie)? Si oui, comment avez-vous utilisé l'information du résumé de preuves?

_____
_____
_____
_____

Section C – Contenu du résumé de preuves:

Encerclez le nombre qui correspond à votre réponse et ajoutez des commentaires supplémentaires, si vous le voulez.

11. Le résumé de preuves était écrit clairement et simple à comprendre.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer le résumé de preuves à cet égard?

12. Le résumé de preuves m'a donné de nouvelles informations sur différentes stratégies pour soutenir la sexualité des adultes ayant une déficience intellectuelle.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer le résumé de preuves à cet égard?

13. L'information du résumé de preuves a informé les discussions du groupe de discussion avec partie prenantes.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer le résumé de preuves à cet égard?

14. Quelles informations (s'il y a lieu) devraient être supprimées du résumé de preuves?

15. Quelles informations (s'il y a lieu) devraient être ajoutées au résumé de preuves?

16. S'il-vous-plaît, partagez tout commentaire supplémentaire sur la distribution et le contenu du résumé de preuves.

_____
_____
_____

Section D – Exécution de la discussion entre parties prenantes:

La discussion entre les parties prenantes était une rencontre d'une demi-journée pour discuter des stratégies dans le résumé de preuves, pour choisir une stratégie et pour choisir une équipe de mise en pratique de la stratégie à l'AISO.

17. Il y avait une bonne distribution de directeurs, gestionnaires, personnel de soutien, personnes ayant une déficience intellectuelle, et des aidants durant la rencontre.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la distribution des participants?

_____
_____
_____

18. Durant la discussion entre parties prenantes, j'ai eu la chance de partager mes opinions.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la discussion à cet égard?

_____
_____

19. Durant la discussion entre parties prenantes, mes opinions ont été discutées et considérées.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la discussion à cet égard?

_____
_____

20. Les désaccords ont été résolus efficacement durant la discussion entre parties prenantes.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord	NA
1	2	3	4	5	0

Comment peut-on mieux améliorer la résolution des problèmes?

_____
_____
_____

Comment peut-on améliorer la discussion à cet égard?

_____
_____
_____

21. L'objectif de la discussion entre parties prenantes est de soutenir une discussion en considérant toutes les informations pertinentes (incluant des preuves scientifiques) sur un sujet d'importance pour inciter l'action. Est-ce que la discussion entre parties prenantes a atteint son objectif?

Échoué	Moyennement échoué	Neutre	Moyennement réussit	Réussit
1	2	3	4	5

Comment peut-on pu mieux soutenir la discussion?

_____
_____
_____

Section E – Contenu de la discussion entre parties prenantes:

22. La discussion entre parties prenantes a permis de discuter de stratégies avec différents niveaux de preuves pour résoudre un problème.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Qu'est-ce qui aurait pu être changé afin d'avoir une meilleure discussion?

_____
_____
_____

23. La discussion entre parties prenantes a permis de discuter d'informations importantes clés pour la mise en pratique.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Quels étaient les informations manquantes?

_____
_____
_____

24. Quels aspects de la discussion entre parties prenantes étaient utiles pour choisir une stratégie à mettre en pratique pour mieux soutenir la sexualité de personnes ayant une déficience intellectuelle? Pourquoi est-ce que ces aspects sont bénéfiques?

_____
_____
_____
_____

25. Quels aspects de la discussion entre parties prenantes n'étaient pas utiles pour choisir une stratégie à mettre en pratique pour mieux soutenir la sexualité de personnes ayant une déficience intellectuelle? Pourquoi est-ce que ces aspects n'étaient pas bénéfiques?

_____
_____
_____
_____

Merci de votre participation!

Appendix G1: Process Evaluation Questionnaire for Persons with ID and Caregivers

Numéro d'identification : _____ Date : _____

Section A –Informations contextuelles:

11. Âge: _____

12. Sexe:

- □ Homme
- □ Femme
- □ Autre

13. Rôle:

- □ Membre de l'AISO
- □ Aidants

14. Depuis comment longtemps recevez-vous des services de l'AISO :

- □ Moins de 2 ans
- □ Entre 2 à 5 ans
- □ Entre 5 et 10 ans
- □ Plus de 10 ans

Le chercheur (ou un bénévole) va compléter le questionnaire individuellement avec les membres de l'AISO. Utiliser un support visuel montrant la différence entre les choix 1 à 5 lorsque les membres de l'AISO remplissent le questionnaire (voir Annexe K).

Exécution de la discussion entre parties prenantes:

La discussion entre les parties prenantes était une rencontre d'une demi-journée pour discuter des stratégies dans le résumé de preuves, pour choisir une stratégie et pour choisir une équipe de mise en pratique de la stratégie à l'AISO.

1. Il y avait une bonne distribution de directeurs, gestionnaires, personnel de soutien, personnes ayant une déficience intellectuelle, et des aidants durant la rencontre.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment aurions-nous pu améliorer la distribution des participants?

_____

_____

_____

2. Durant la discussion entre parties prenantes, j'ai eu la chance de partager mes opinions.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la discussion à cet égard?

_____

_____

_____

3. Durant la discussion entre parties prenantes, mes opinions ont été discutées et considérées.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la discussion à cet égard?

_____

_____

_____

4. Les désaccords ont été résolus efficacement durant la discussion entre parties prenantes.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord	NA
1	2	3	4	5	0

Comment les problèmes ont-ils été résolus?

_____
_____
_____
_____

Comment peut-on améliorer la discussion à cet égard?

_____
_____

5. L'objectif de la discussion entre parties prenantes est de soutenir une discussion en considérant toutes les informations pertinentes (incluant des preuves scientifiques) sur un sujet d'importance pour inciter l'action. Est-ce que la discussion entre parties prenantes a atteint son objectif?

Échoué	Moyennement échoué	Neutre	Moyennement réussit	Réussit
1	2	3	4	5

Comment aurions-nous pu mieux soutenir la discussion?

_____
_____
_____
_____

<u>Section E – Contenu de la discussion entre parties prenantes:</u>

6. La discussion entre parties prenantes a permis de discuter de stratégies avec différents niveaux de preuves pour résoudre un problème.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement	Tout à fait d'accord

			d'accord	
1	2	3	4	5

Qu'est-ce qui aurait pu être changé afin d'avoir une meilleure discussion?

_____
_____
_____
_____

7. La discussion entre parties prenantes a permis de discuter d'informations importantes clés pour la mise en pratique.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Quels étaient les informations manquantes?

_____
_____
_____
_____

8. Quels aspects de la discussion entre parties prenantes étaient utiles pour choisir une stratégie à mettre en pratique pour mieux soutenir la sexualité de personnes ayant une déficience intellectuelle? Pourquoi est-ce que ces aspects sont bénéfiques?

_____
_____
_____
_____
_____

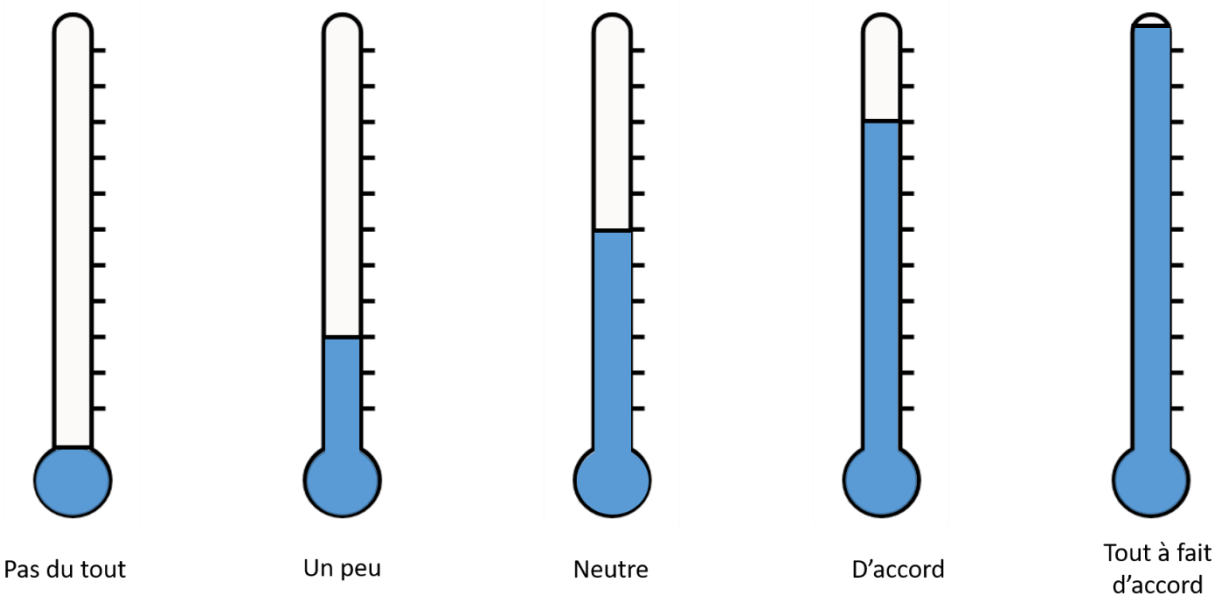
9. Quels aspects de la discussion entre parties prenantes n'étaient pas utiles pour choisir une stratégie à mettre en pratique pour mieux soutenir la sexualité de personnes ayant une déficience intellectuelle? Pourquoi est-ce que ces aspects n'étaient pas bénéfiques?

_____
_____
_____
_____
_____

Merci de votre participation!

Appendix G2: Visual Aid for Adults with ID

Échelle pour le questionnaire pour le dialogue entre parties prenantes



Appendix H: Process Evaluation Questionnaire for Sexual Education Workshops

Numéro d'identification : _____ **Date:_____**

Section A –Informations contextuelles :

15. Âge: _____

16. Sexe:

- ☐ Homme
- ☐ Femme
- ☐ Autre

17. Rôle:

☐ Membres de l'AISO

☐ Direction/Gestion – Précisez le poste : _____
- Services résidentiels
- Soutien aux adultes
- Participation communautaire
- Soutien à l'emploi
- Services de répit

☐ Personnel de soutien – Précisez le poste : _____
- Services résidentiels
- Soutien aux adultes
- Participation communautaire
- Soutien à l'emploi
- Services de répit

18. Depuis comment longtemps occupez-vous ce poste / recevez-vous des services de l'AISO :

- ☐ Moins de 2 ans
- ☐ Entre 2 à 5 ans
- ☐ Entre 5 et 10 ans
- ☐ Plus de 10 ans

Section B – Contenu des formations:

L'AISO a accepté de contribuer à un projet de recherche pour comprendre comment les connaissances découlant de la recherche au sujet du soutien à la sexualité des personnes ayant une déficience intellectuelle sont mises en pratique dans des agences de services communautaires. Dans le cadre de ce processus, cette formation sur la santé sexuelle a été donnée le *DATE*. Cette formation avait pour but de partager de nouvelles connaissances sur la santé sexuelle.

Encerclez le nombre qui correspond à votre réponse et ajoutez des commentaires supplémentaires, si vous le voulez.

26. Le contenu de la formation était clair et simple à comprendre.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la formation à cet égard?

_____
_____
_____

27. La formation m'a donné de nouvelles informations sur la sexualité.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la formation à cet égard?

_____
_____
_____

28. L'étendu du contenu était appropriée.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Quelles informations (s'il y a lieu) devraient être supprimées de la formation?

Quelles informations (s'il y a lieu) devraient être ajoutées à la formation?

29. S'il-vous-plaît, partagez tout commentaire supplémentaire sur le contenu de la formation.

Section C – Format de la formation:

30. La représentation des membres et du personnel de l'AISO était bénéfique pendant la formation.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la représentation des participants?

31. Les études de cas étaient claires et simple à comprendre.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la formation à cet égard?

32. Les discussions étaient claires et simple à comprendre.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la formation à cet égard?

_____
_____
_____

33. Les activités m'ont permis de pratiquer ce que j'ai appris durant la formation.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la formation à cet égard?

_____
_____
_____

34. Durant les activités, j'ai eu la chance de poser mes questions.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment peut-on améliorer la formation à cet égard?

_____
_____
_____

35. Qu'avez-vous le plus aimé durant la formation?

_____
_____
_____

36. Que faut-il améliorer durant la formation?

_____
_____
_____

37. Comment pensez-vous utiliser le contenu de la formation?

_____
_____
_____

38. Avez-vous d'autres commentaires?

_____
_____
_____

Section D – Pour formateurs:

39. J'ai appris à donner une formation.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Qu'as-tu appris durant la formation?

_____
_____
_____

40. J'aimerais donner d'autres formations.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Pourquoi? Sur quels thèmes?

_____

_____
_____

41. Je vais pouvoir utiliser les habiletés que j'ai apprises en tant que formateur.

Pas du tout d'accord	Plutôt pas d'accord	Neutre	Moyennement d'accord	Tout à fait d'accord
1	2	3	4	5

Comment pourrais-tu utiliser ou pas tes habiletés en tant que formateur.

_____
_____
_____

42. Autres commentaires?

_____
_____
_____

Merci de votre participation!

Appendix I: Process Evaluation Questions and Methods

Activity	Specific Question	Data sources
All main activities (Applies to all sections below)	• Were the steps of the KT intervention completed as intended? • How did the intended and actual interventions differ? • What led to these differences?	• Intended versus actual logic model • Memos throughout the process about challenges and facilitators
Scoping Review	• What facilitated the process? • What hindered the process?	• Primary researcher notes and scoping review findings
Writing Evidence Brief	• Does the evidence brief include the sections as outlined in the proposal? • How does it differ?	• Intended evidence brief versus actual

Distributing Evidence Brief	• Was the KT intervention completed as intended?
	• What were the strengths of implementation?
	• What were the barriers or challenges in implementation?
	  • Did the recipients understand the intervention?
	  • What were staff perceptions?
		• Questionnaire.
		Example questions:
		  ○ Demographic information (age, gender, etc.)
		  ○ How many people received it?
		  ○ How many people read it?
		  ○ Did you understand it?
		  ○ Was it useful? (Did you understand the topic better? Did it inform the stakeholder dialogue?)
		  ○ What else would you have wanted to be included?
		  ○ What was not necessary?
		  ○ Should it have been distributed at a different time? In another way?
		  ○ General impressions of the content and the way it is written

Activity	Specific Question	Data sources
Focus Groups	• Was the KT intervention completed as intended? • What was the nature of the interactions between participants? • Did participants have similar or different views? • How was their communication and interactions? • Were there some people who dominated the discussion?	• Basic demographic information • Transcriptions of focus groups • Notes of undergraduate observers • Notes of the primary researcher
Stakeholder Dialogue	• Was the KT intervention completed as intended? • Were all topics covered as outlined? • How did the intended and actual interventions differ? • What led to these differences? • What was the nature of the interactions between participants? • Did participants have similar or different views? • How was their communication and interactions? • Did everyone get to voice their opinions? Did some people dominate? • Was information from the focus group incorporated into the final decision? • How were decisions made? How was consensus achieved?	• Transcription of stakeholder dialogue • Notes of undergraduate observers

Activity	Specific Question	Data sources
Stakeholder Dialogue (cont.)	• Did representatives from the focus groups feel like their opinions were considered and incorporated? • What were the benefits of the stakeholder dialogue? Why were these things perceived to be beneficial? • What were the challenges of the stakeholder dialogue? Why were these things perceived to be challenging? • Were problems successfully resolved? How so?	• Questionnaire
Implementation	• Was the KT intervention completed as intended? • What was the nature of the interactions between participants? • Did participants have similar or different views? • How was their communication and interactions? • Did everyone get to voice their opinions? Did some people take charge? Was a hierarchy formed, or did people contribute equally? • How were decisions made? How was consensus achieved? • What was challenging during the process? Why? • What was helpful during the process? Why? • Were problems successfully resolved? How so?	• Bi-weekly meeting minutes • Transcription of implementation team meetings • Questionnaires at the end of the implementation • Notes of undergraduate observers