THE SOCIO-SEXUAL KNOWLEDGE AND ATTITUDES ASSESSMENT TOOL – REVISED: THE NEED FOR UPDATES IN ASSESSMENT FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

by

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Abstract

The current document is a paper-based thesis which examined the Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised (SSKAAT-R) for individuals with intellectual disabilities in order to inform the development of a revision. The first paper is a descriptive overview of topics of sexuality that are considered important for assessment and education in the year 2020. Findings revealed that inappropriate physical contact, incest and inappropriate sexual contact, intercourse, homosexuality, and birth control were some of the most important topics to consider for individuals with an intellectual disability in the year 2020. In addition, the first paper compared these findings to the topics which were identified as important twenty and forty years ago in order to note changes that have occurred over time. The second paper examined the content of the SSKAAT-R, specifically. Strengths and weaknesses voiced by professionals who use the tool are highlighted. Overall, the mixed methods findings included in this thesis indicate that many aspects of the SSKAAT-R are appreciated, such as the visual content and its ability to touch on a variety of topics pertaining to sexuality. Conversely, some areas - such as the outdated pictures, as well as the lack of information regarding internet safety and sexual and gender minorities - were highlighted as limitations. Suggestions for future research and clinical implications are discussed.

Keywords:

The following terms are critical to the current thesis entitled, “The Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised: The Need for Updates in Assessment for Individuals with Intellectual Disabilities”: intellectual disability, sexuality, sexual knowledge, socio-sexual education, and assessment.

Statement of Co-Authorship

I declare that this thesis includes materials that are a result of joint research collaborations. The following includes a list of the publications containing material produced in this thesis, with the nature and scope of work from co-authors.

Gessie, K., Watson, S. L., Harding, K. D., & Lunsky, Y. (in preparation). Socio-sexual assessment and education for individuals with intellectual disabilities: a twenty- and forty- year comparison. *Journal on Developmental Disabilities*.

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The following contributions apply to both manuscripts listed above:

K. Gessie developed the research questions, acquired the data, conducted the data analysis, and wrote the manuscripts.

S. L. Watson and K. D. Harding were the Master's supervisors supporting the primary investigator (K. Gessie) and providing extensive feedback and revisions for both documents.

Y. Lunsky was the Master's committee member and provided extensive feedback and revisions for both documents.

I certify that this thesis - and the research to which it refers - is the product of my own work.

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Chapter 1: Introduction

This study examined the Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised (SSKAAT-R; Griffiths & Lunsky, 2003) for individuals with intellectual disabilities (ID). The SSKAAT-R assesses the knowledge and attitudes of individuals with ID with respect to sexuality and is a revision of the Socio-Sexual Knowledge and Attitudes Test (SSKAT; Wish et al., 1979). Given that the SSKAAT-R was published eighteen years ago, and issues related to sexuality evolve overtime, the SSKAAT-R should be evaluated as an update is in order for the tool. This study ascertained what changes should be made in order to better assess and understand sexuality concerns and contribute to a new, revised version, the SSKAAT-3. Specifically, this research identified potential enhancements or changes that should be made to the SSKAAT-R in order to update the manual and to better assess the sexual knowledge and attitudes of individuals with ID. Also, the current study identified which components should remain the same according to psychologists, clinicians, and staff members who work with individuals who have ID.

1.1 Background of the Problem

Throughout history, the sexuality of individuals with ID has largely revolved around prejudice, neglect, and misunderstanding. Although these individuals possess the same sexual needs and wants as any other individual in the general population, persons with ID have repeatedly and systemically been denied their sexual rights (Cuskelly & Bryde, 2004; Di Giulio, 2003; Richards et al., 2006; Watson et al., 2002). These sexual rights are being denied as a result of misconceptions and negative societal attitudes regarding the sexuality of persons with disabilities and their possible criminal, promiscuous, and sexually deviant behaviours (Di Giulio, 2003). Specifically, societal opinion has presumed that individuals with ID are not capable of

appropriately expressing their sexuality or that they are incompetent in their roles as sexual beings. As a result, this type of thinking has led to these individuals being restricted from engaging in sexually productive and full lives. People with ID have been subjected to sexual segregation, sexual confinement, marital prohibition, and legally sanctioned sterilization under the assumption that it would serve as protection from pregnancy and sexual abuse (Block, 2000; Kempton & Kahn, 1991). Additionally, there are many misconceptions and fallacies surrounding the sexuality of people with ID, such as the belief that they are asexual, meaning they do not/should not have sexual needs and feelings. Conversely, these individuals have also been categorized as hyper-sexual or having an excess of sexual desire (Block, 2000; Brodwin & Frederick, 2010; Noonan & Taylor Gomez, 2011; Swango-Wilson, 2008). Today, people with ID are still denied complete sexual rights because of the persistence of these negative attitudes (Stinson et al., 2002).

1.2 Literature Review

In the current literature review, several important topics were explored pertaining to individuals with ID and their knowledge of, and attitudes towards, sexuality. First, the sexual rights of persons with disabilities was explored. Second, the meaning of sexuality for this population was described, as is the perception held by others of this population's sexuality. Last, this literature review described possible issues regarding a lack of sexual knowledge for these individuals, and the importance of sociosexual education and assessment tools employed by clinicians in the field.

1.2.1 Sexual Rights

Nussbaum (2014) characterizes sexuality as a fundamental human right that requires "having the opportunity for sexual satisfaction and choices about reproduction" (p. 57).

Nussbaum also states that it is absolutely crucial to protect this right. Indeed, the expression of sexuality, which includes how individuals create and maintain intimate relationships, is a constitutional part of being human (Krebs, 2007; Matich-Maroney et al., 2005; World Health Organization, 2013). In health and social care settings, now more than ever, professionals in the field are paying more attention to problems related to sexuality (Greenhill & Whitehead, 2011; McCann, 2010; Palumbo, 2016).

As do all human beings, people with ID have human rights (Stainton & Clare, 2012), which includes sexual rights. According to the *United Nations Convention on the Rights of Persons with Disabilities* (United Nations, 2006), healthy sexuality is a necessity for mental wellness and includes two components: 1) the ability to enjoy and control sexual and reproductive behaviour within the parameters of social and personal ethics; and 2) freedom from fear, shame, or other psychological factors that may inhibit sexual expression. The *United Nations Conventions on the Rights of Persons with Disabilities* (United Nations, 2006), maintains very clearly in Article 23 (Respect for home and the family) that:

a. The right of all persons with disabilities who are of marriageable age to…found a family on the basis of free and full consent…is recognized.
b. The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them…are provided.

This recognition for the home and family life of all persons with ID is also an acknowledgement of the importance of the quality of life of all member citizens and, more generally, all people. In connection to the respect for home and the family, Article 19 states that

individuals with disabilities have the right to decide where they live and with whom, and Article 22 recognizes and protects the right to privacy (United Nations, 2006). Furthermore, it is important to note that sexuality is also a health issue. Effectively, Article 25 recognizes the right to health with very specific regulations: individuals with ID need to be informed of their rights as sexual beings, as well as taught how to consent if they are not initially able to. Other pertinent sections include Article 21 on the access to information and Article 24 on the right to education, as well as Article 16, the right to freedom from exploitation, violence and abuse (United Nations, 2006). This latter Article is particularly crucial as individuals with ID are at a high risk for sexual abuse.

Elsewhere, the World Association for Sexual Health (2014) has made clear the range and specificity of sexual health rights. These include the right to privacy, the right to sexual health, the right to marriage and to start a family, the right to decide on the number of children, the right to information and education, the right to freedom of opinion and expression, and the right to the protection of these rights. According to the American Association on Intellectual and Developmental Disabilities (AAIDD, 2008), it is necessary for these sexual rights to be affirmed, defended, and respected. However, Richards and colleagues (2009) concluded that sexuality is a complex and often unresolved issue due to the imposition of a social construct and the continued pathologizing of the disabilities themselves. In other words, individuals with ID find it challenging to exercise their sexual rights because they and their sexuality are often stigmatized or misunderstood.

Also, individuals with ID do not always get the respect and support that they require (Ignagni et al., 2016; Watson et al., 2002). Individuals with ID are more likely than the general population to have negative sexual experiences or to be sexually abused (Abbott & Howarth

2005; Eastgate et al., 2011; Hickson et al., 2008; Reiter et al., 2007; Stoffelen et al., 2013; Van Berlo et al., 2011). Furthermore, people with ID encounter problems when it comes to exercising their sexual rights (Bernert 2011; McGuire & Bayley 2011), such as the right to adequate privacy. Specifically, the need for privacy in residential settings is often poorly acknowledged (Hollomotz & Speakup Commitee, 2009). In fact, it has been established that family members as well as support providers tend to set different standards for themselves than for individuals with ID (Christian et al., 2001; Swango-Wilson 2008; Yool et al., 2003). In this context, a disconnect can be observed between what is considered acceptable for individuals with ID and what is acceptable for those without ID.

1.2.2 The Rights Agenda

Richards, Watson, Monger, and Rogers (2012) created the *Rights Agenda Recommended Pathway to Achieve Sexual Autonomy for People with Disabilities.* This document provides a clear picture of what needs to be achieved to fully implement the sexual rights enshrined in the *United Nations Convention on the Rights of Persons with Disabilities*. Specifically, the authors developed a total of four criteria as a means of working towards each person being able to employ their sexual rights. This approach involves sexual education and knowledge, support for each person using a person-centered methodology, empowering people to increase self-awareness and decision making, and the provision of opportunities that are conductive to healthy sexuality. These authors affirm that if these four specific criteria are met, individuals with ID will have the knowledge that is required to make responsible decisions and, therefore, be in a position to engage in romantic relationships of their choice.

First, the attitudes held by health care providers with respect to sexuality and disability are essential components in creating positive change for individuals with ID. Although there is

an obligation and responsibility within agencies to train all care providers to support individuals with disabilities in a consistent manner, Drummond (2006) reported that traditional attitudes of primary care providers presented obstacles that decreased the likelihood of providing opportunities for sociosexual education. Sociosexual education can encompass techniques, strategies, programs, and interventions that are designed to promote appropriate sexual behaviour and overall good health and well-being (Griffiths, 2003). Sociosexual education can be formal or informal. For example, Griffiths (2003) speaks about "teachable moments" as a form of informal sociosexual education. Examples of these moments could be family members and support staff workers who build normative social learning opportunities which are essential to learning about one's immediate environment. Furthermore, Volkmar and Wiesner (2009) mention that carefully planned and supervised mixed gender events and social skills groups are great first steps for young people with autism spectrum disorder, specifically. The key here is to keep discussions open among individuals, as well as make rules for socially appropriate behaviours very clear to understand (Volkmar & Wiesner, 2009). *The Convention on the Rights of Persons with Disabilities* explicitly states that individuals with disabilities have a right to the same education and sexual health related services as those who do not have a disability (United Nations, 2006).

Second, according to Walker-Hirsch (2007), people have a good chance to live well if their lives have been built around a range of relationships. Walker-Hirsch (2007) suggests that happiness is directly related to the quality of our relationships with others. With that said, individuals with ID often have difficulty developing relationships for reasons that range from physical constraints to cognitive abilities and restricted living arrangements. Support is also imperative in the context of fostering diversity with respect to sexual orientation. Allen (2007) states that fostering diversity should be done in such a manner that "validates their feelings,

builds self-esteem and counters some of the negative messages they may hold" (p. 166). Supporting individuals with ID who also identify as LGBTQ+ is also vitally important; regrettably, these are persons who often report having a sense of isolation and loneliness (Allen, 2007).

Third, in order to empower people with ID, we must progress away from the historical practices of conformity and control. It is through building confidence and self-esteem that these individuals will acquire a positive self-view and autonomy, plus will enhance their ability to make appropriate sexual decisions. It is especially important to build skills through empowerment at a younger age, as this will permit children and adolescents to make age-appropriate decisions on their own. Being able to make these decisions earlier in life ultimately increases competency for these individuals in their later years. For instance, knowledge and skills provide one with the power to distinguish between right and wrong, safe and unsafe situations, and when to choose to consent or not to consent. Isler and colleagues (2009) stated that "sexuality education empowers children with disabilities to enjoy personal sexual fulfillment and to protect themselves from abuse, unplanned pregnancies and sexually transmitted disease" (p. 28).

Last, once education, supports, and empowerment have been effectively implemented, the next step is to provide opportunities for people to begin socializing and meeting new people. These opportunities need to be proven and sustainable and they must ensure that all people with ID receive the same social connections that members of mainstream society enjoy. For example, care providers should encourage communication through traditional methods such as telephones and computers, role-play to teach good conversational skills, assistance with phone calling (if they are unable to), and encouragement toward routine contact with valued individuals. With that

said, it is important to identify barriers to social well-being such as transportation, communication skills, finance, and/or physical needs. These barriers can often prevent people with ID from developing and maintaining a life that includes healthy relationships and healthy sexuality. It is also important that service providers, families, and care providers involved in an individual's life are not obstacles themselves to these desired outcomes. Rather, this support network must be a *gateway* for individuals with ID toward meaningful relationships and sexuality (Richards et al., 2012).

1.2.3 Perceptions of Others About Individuals with Intellectual Disabilities and Their Sexuality

Historically, it has been demonstrated that attitudes toward the sexuality of people with ID are usually much less positive than those demonstrated toward typically developing adults (Cuskelly & Bryde, 2004). Although sexuality often plays a crucial role in human life, it is not uncommon for it to be stigmatized, discouraged and, frankly, unattainable to many individuals with an ID (Ditchman et al., 2016). In fact, significant stereotypes still exist according to which individuals with an ID are child-like, naïve, or asexual (Jahoda et al., 2010). Of course, these misconceptions have had a negative impact on this population with respect to freedom for intimate relationships, reproduction, and the advancement of sexual health and safety (Esmail et al., 2010; Isler et al., 2009; Murphy & Young, 2005; Scotti et al., 1996).

Sinclair, Unruh, and Lindstrom (2015) conducted a review examining the sexuality of individuals with ID. The authors identified possible barriers for this population that are preventing them from achieving the same autonomy and quality of life as their peers. Specifically, the authors described barriers that have been experienced by individuals with ID in gaining knowledge of sexuality, sexuality-related topics, and the experience of relationships.

Sexuality was defined broadly to include biological, social, psychological, spiritual, ethical, and cultural dimensions. It was stated that this definition captures the multiple dimensions of sexuality and allows the authors to look beyond access to only biological sex education. The authors identified three barriers: misunderstandings with respect to the sexuality of individuals with ID; lack of consistency across providers; and lack of responsibility to educate.

First, there can be misunderstandings held by others about the sexuality of individuals with ID. For example, parents and caregivers may hold the misperception that individuals with ID are asexual or uninterested in sex. In one case, the parent of a child with an ID stated to researchers that "their child was not interested [in sex]," even if the parent recognized that sex was an important part of life in general (Swango-Wilson, 2009, p. 226). The purpose of this study was to discover the expectations for a sex education program identified by individuals with ID, parents of individuals with ID, as well as professionals who work with individuals with ID. Results showed that parents, in particular, were in denial that their child with a disability could even be remotely thinking about or interested in sexual relationships (Swango-Wilson, 2009). In another study where researchers questioned a participant without a disability about a relationship with an individual with a disability, the participant responded by saying they would not want to begin a relationship with someone with a disability for fear of becoming a caregiver to the individual with a disability (Esmail et al., 2010).

A second barrier identified by Sinclair and colleagues (2015) was the lack of consistency among providers on what topics should be addressed and how to approach educating individuals with ID regarding their sexuality. The perception of how to educate these individuals changed depending upon the role the service provider had in their interaction with persons with ID. Importantly, across professional and personal roles, there was no consensus as to what the

primary goal should be when discussing sexuality and sex education for the individuals with disabilities that they serve. Specifically, physicians and health professionals were concerned about covering topics such as pregnancy, sexually transmitted infections, and other reproductive health matters (Esmail et al., 2010). Independent living center service providers were concerned about the safety of their clients and feared legal ramifications from parents for unapproved sexual behaviours, even though the individuals they cared for were over 18 years of age (Bernert, 2011; Esmail et al., 2010). Parent responses seemed to be more focused on sexual abuse and unwanted pregnancy; for example, "I fear sexual abuse . . . he is so trusting" (Swango- Wilson, 2009, p. 226) and, "if she had a baby, I don't think I could raise another one" (Swango-Wilson, 2009, p. 226). Overall, one can summarize that the views of service providers and parents resulted in restrictions on relationships and personal encounters for individuals with ID (Bernert, 2011; Esmail et al., 2010; Swango-Wilson, 2009).

The third barrier identified was the lack of responsibility to educate individuals about sexuality. Parents are often identified as the primary sex educators for individuals with and without disabilities (Murphy et al., 2016). However, there is a lack of understanding of what and how much sexual education does and does not occur at home. Although instructors who worked with young adults over the age of 21 felt comfortable assuming the role of sex educator for individuals with ID, high school teachers were less inclined to take on that responsibility (Wilkenfeld & Ballan, 2011).

Another study demonstrated the stigma that exists with respect to the sexual lives of people with ID. Even though this population reported being sexually active, they also understood that this was not approved of by others (Hillier et al., 2002). Esmail et al. (2010) caution that limited access to information can further perpetuate misperceptions among individuals with

disabilities; consequently, these misconceptions might engrain stigmatizing beliefs (such as asexuality) into one's self-concept, affecting, moreover, self-confidence, sexual functioning, and relationships. Considering that limited access to information can preserve negative societal attitudes towards individuals with intellectual disabilities, it is crucial to examine their actual scope of knowledge on the topic of sexuality.

1.2.4 Knowledge on Sexuality

In general, researchers have found that sexual knowledge among people with ID is often lacking, but it is important to note that there is considerable individual difference and variability in the level of knowledge (Eastgate et al., 2011; Galea et al., 2004; Siebelink et al., 2006). Available research shows that adults with ID not only present, on average, with lower levels of knowledge than people without disabilities (Szollos & McCabe, 1995), but they can also hold negative views towards sex (Bernert & Ogletree, 2013). At the same time, many people with ID have sexual needs and hope to be in a relationship (Kelly et al., 2009). Researchers have also shown that many individuals with ID, especially with mild impairments, are sexually active (McCabe, 1999; McGillivray, 1999). However, sex education is not always available (Milligan et al., 2012), which may have many negative consequences, such as increased risk of sexually transmitted infections (Aderemi et al., 2013).

Earlier studies have shown limitations in sexual knowledge. Hillier and colleagues (2002) demonstrated that many participants reported that formal education about sex was lacking and those who had received such education had not found it helpful. McCabe and colleagues (e.g., McCabe & Cummins, 1996; Szollos & McCabe, 1995) have found lower levels of knowledge of sexual matters among those with an ID than among comparison groups of psychology students. Szollos and McCabe (1995) also found that caregivers significantly overestimated their clients'

knowledge in a number of areas related to sexuality. They concluded that adults with an ID lacked sufficient knowledge about sexual matters to protect themselves against exploitation. In a more recent study where the sexual understanding of 30 adolescents with intellectual disabilities was compared to a group of 30 adolescents without disabilities, it was reported that the individuals without a disability had higher levels of knowledge (Jahoda & Pownall, 2014).

Despite the fact that more caregivers and professionals are starting to believe that sex education is needed (e.g., Lafferty et al., 2012), many of them experience worries and confusion about discussing the topic of sexuality and relationships. The worry or confusion is often due to concerns about causing harm, or beliefs that providing sex education will lead to inappropriate sexual behaviour (Rohleder, 2010). In a study conducted by de Reus and colleagues (2015), educators working with individuals with ID recognized a number of challenges in their work, including barriers in communication and language, cultural values and expectations, learners' knowledge and behaviour, handling of sexual abuse cases, and the life experiences of the teachers themselves. In addition, many educators and teachers reported not feeling properly trained (Christian et al., 2001). It is also common for parents of adolescents with ID to resist discussing sex with their kids (Pownall et al., 2012).

1.2.5 Consequences of Limited Sexual Knowledge

There are many significant consequences of low levels of sexual knowledge among people with ID. First, inadequate and incomplete knowledge likely contributes to the fact that people with ID are at greater risk of abuse (Swango-Wilson, 2009). In contrast to individuals with average IQ or above, individuals with ID are more likely to experience sexual abuse (Fisher et al., 2016) and less likely to report it (Chave-Cox, 2014; Fodgen et al., 2016). The authors of a recent literature review suggest that from 7% to 34% individuals with ID have experienced

sexual abuse in adult life (Smit et al., 2019). It is also estimated that, of this population, 83% of females and 32% of males have, at one point in their lives, been victims of sexual abuse. Historically, this general lack of understanding of sex created conditions in which individuals with ID were easy targets for abuse (Conod & Servais, 2008). Sadly, they may not fully understand what is being done to them. For this reason, sexual abuse prevention is a critical section of sociosexual education and should be considered part of a comprehensive pedagogical plan for individuals with ID. In addition, it would be important for educators to focus on the legal components of sex and sexuality as it has been reported that approximately 50% of adults with ID simply were not aware that laws against rape and sexual assault even applied to them (Murphy and O'Callaghan, 2004).

Second, a limited knowledge of sexuality increases the risk of contracting sexually transmitted infections (Aderemi et al., 2013). Researchers have consistently found that individuals with ID have low levels of knowledge with respect to sex, contraception, pregnancy, sexually transmitted infections, and sexual intimacy (Cheng & Udry, 2003; Gougeon, 2009; Isler et al., 2009; McCarthy, 2009; Plaute et al., 2002; Servais, 2006). Taking this into consideration, the health of those with ID is clearly at risk by this lack of knowledge. For instance, in their survey, Murphy and O'Callaghan (2004) found that 50% of adults with ID did not know the purpose of condoms, while 37% only partially knew their function. Also, in Murphy and O'Callaghan's (2004) survey, it was reported that less than 2% of participants gave correct answers explaining what AIDS was. Conod and Servais (2008) also found that nearly 41% of women with ID did not use any form of contraceptive methods.

Third, some authors have found that limited sexual knowledge might account for the sexual offenses of some people with ID (Barron, et al., 2002). However, other scholars contend

that offenders present the same or even higher levels of knowledge than people with no known history of sexual offending (Lockhart et al., 2010; Lunsky et al., 2007; Michie et al., 2006; Talbot & Langdon, 2006). Dukes and McGuire (2006) showed in their research that the higher the level of knowledge, the greater the capacity to make sexuality-related decisions. The "counterfeit deviance" theory was first proposed by Hingsburger, Griffiths, and Quicy (1991) and was noted by Luiselli (2000) to be the most influential basis for the development of treatment services for this client group. The term "counterfeit deviance" refers to behaviour which is undoubtedly deviant, but may be precipitated by factors such as lack of sexual knowledge, poor social skills, limited opportunities to establish sexual relationships, and sexual naivety, rather than a preference for, or sexual drive towards, inappropriate objects. Griffiths and colleagues (2013) reviewed the "counterfeit deviance" theory in their study of people with ID who sexually offend. The "counterfeit deviance" theory is based on the fact that a number of individuals with ID referred to as sexual offenders present differently than anticipated for someone with paraphilia (Griffiths et al., 2013). In effect, these individuals presented inappropriate behaviours that were the product of different diagnostically significant factors. The theory has never denied paraphilia in persons with ID; however, it does caution against assumptions of paraphilia based only on behaviours (Griffiths et al., 2013).

The "counterfeit deviance" theory includes a total of eleven hypotheses which aim to account for both the individual and the system in which they live. Further, the theory aims to identify the many factors clinicians should consider when diagnosing and treating individuals with ID who exhibit inappropriate sexual behaviour (Griffiths et al., 2013). For instance, the 'sexual knowledge hypothesis' speaks to the lack of appropriate and comprehensive sexual knowledge that is, at times, the cause of inappropriate sexual behaviour. Specifically, a lack of

sexual knowledge may be a factor in understanding why individuals with disabilities may exhibit fondling, exhibitionism, and public masturbation behaviours (Lunsky et al., 2007). Given that this lack of sexual knowledge may result in serious consequences, providing sociosexual education to individuals with ID is absolutely essential for this population.

1.2.6 Sociosexual Education

Learning about sexuality is lifelong. People with ID, just like people without disabilities, will learn about sexuality gradually and throughout the course of their life. In fact, children and adolescents with and without ID benefit greatly when they are provided with accurate and developmentally appropriate information about the biological, sociocultural, psychological, relational, and spiritual dimensions of sexuality (Duncan et al., 2015). Sexual education is a crucial part of the development of every adolescent. With that said, considerable challenges exist in providing effective and appropriate sexual education for adolescents with ID; these may include lack of training of school personnel and lack of adequate materials suitable to meeting the special needs of students (Wolfe & Blanchette, 2002). The purpose of sociosexual education programs are to improve sexual health, which is described not only by the absence of disease or negative experiences regarding sexuality, but also by the prevalence of pleasurable and safe sexual experiences (World Health Organization, 2006). To reiterate, sexual health is not only about preventing sexually transmitted infections (STIs), unplanned pregnancies, and negative sexual experiences, but also about providing people with the opportunity to experience sexuality in a positive way (Schaalma et al., 2009). However, the specific goals of sociosexual education programs must depend upon the needs of the population and the context in which education is provided (Bartholomew et al., 2011).

In order to develop a good understanding of sex and sexuality, adequate and appropriate education is crucial (Richards et al., 2012). As previously mentioned, properly implemented sociosexual education programs should provide a balance between healthy sexual empowerment and the protection of individuals from exploitation (Richards et al., 2012). Hamilton and Atkinson (2009) speak of the general lack of support for sexual education in service agency group homes, concluding that productive practices to aid the capacity to consent to sexual relations are very rare. Isler et al. (2009) found that 51.7% of teenagers with ID in their survey did not have any sexual education at all. In fact, many schools and community agencies do not support sociosexual programs and, if they do, they often do not provide information on a range of important subjects needed for a complete understanding of one's own sexuality (Gourgron, 2009; Griffiths, 2003; Kelly et al., 2009).

Data on the benefits of sexual education programs for persons with ID are beginning to emerge. For example, one research report suggests that sexual education can help people with ID to increase their knowledge and understanding of sexual abuse (Murphy, 2003). McDermott and colleagues (1999) evaluated a sex education program for women with an ID and found that an increase in sexual knowledge was directly associated with a greater number of instructional contacts. The analysis again indicated that the program was effective in improving the sexual knowledge of adults with an ID. Dukes and McGuire (2009) found that sex education is more helpful for individuals with ID when it is individually adapted. Thus, when sexual education is catered to these specific individuals, it increases the ability for individuals with ID to make informed decisions about their sexual relationships. When these individuals are able to make more informed decisions, they are better able to consent to sexual relationships, can make informed choices with respect to birth control, and are less vulnerable to sexual abuse.

1.2.7 Importance of Assessment of Sexual Knowledge, Attitudes, and Needs

In order to provide relevant and complete sociosexual education for individuals with ID, one must be able to assess their current knowledge, attitudes, and needs on the matter. While the assessment of sexual knowledge can be conducted in a number of ways, including games, focus groups, and semi-structured interviews, most studies have used standardized questionnaires in order to determine sexual knowledge (Talbot & Langdon, 2006; Wilson et al., 2014). Research into the sexual knowledge of individuals with ID has resulted in the development of several sexual knowledge assessment tools including *The Human Relations and Sexuality Knowledge and Awareness Assessment* (Family Planning Victoria, 1997), The *Sex Knowledge, Experience, and Needs Scales for People with Intellectual Disabilities* (McCabe, 1994), *The General Sexual Knowledge Questionnaire* (Talbot & Langdon, 2006), as well as *The Assessment of Sexual Knowledge* (ASK; Butler et al., 2003). Butler, Leighton and Galea (2003) propose that such assessment tools should be used to identify gaps in the sexual knowledge of people with ID, and recommend that these identified gaps should be addressed through individually tailored sexual health educational programs.

Many studies that have employed pre- and post-sexual knowledge assessments have been able to demonstrate an increase in the sexual knowledge of people with ID following sexual health education (Dukes & McGuire, 2009; Murphy et al., 2007; Wells et al., 2012). For example, the purpose of Watson's (2002) study was to highlight data on the sexual knowledge and needs of individuals who have an ID. The data was collected before and after a sex education program to determine if there was a change in knowledge after education. It was found that individuals who received sexuality education increased significantly in knowledge; more

specifically, participants in the sex education group increased their knowledge dramatically on both the SSKAT (Wish et al., 1980) and the SSKAAT-R (Griffiths & Lunsky, 2003).

In a study conducted by Thompson and colleagues (2016), semi-structured interviews were conducted with clinicians who use sexual knowledge assessment tools. According to this study, and with respect to individuals with ID, clinicians used these assessment tool results to write a report with a set of recommendations. These recommendations were typically for support staff to facilitate interaction with someone whose sexual knowledge was being assessed and/or to develop an education program. It was noted that those that developed sexual education programs used the tools to determine what is to be taught. Topics included in these education programs are largely limited to those covered in the assessment tools. However, when asked how influential the assessment tools are in determining what topics will be utilized in education programs, one clinician responded: “It forms a large part. I guess it’s a standardized measure of what we can teach and what we shouldn’t” (Thompson et al., 2016, p. 247).

1.2.8 The Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised

In 1980, the Socio-Sexual Knowledge and Attitude Test (SSKAT) was published based on research carried out in the 1970s with men and women with ID living in both institutions and the community. To assist them in selecting items for the test, the authors surveyed parents, educators, and institutional and community-based clinicians about their opinions on the importance of various topics for inclusion in assessment and education (Wish et al., 1979). They reported that the most important topics for sex education were birth control information, intercourse, venereal disease (i.e., how these are contracted, their symptoms, and who to tell), and pregnancy (i.e., how to become pregnant and how to prevent it). Avoiding street pick-ups and inappropriate physical contact were also ranked as very important (Wish et al., 1979).

In 1999, Griffiths and Lunsky distributed the Wish et al. (1979) questionnaire to persons who worked closely with individuals with ID, including parents, educators, and institutional and community-based clinicians of persons with ID. Redistribution occurred at four educational events on the topic of sexuality and persons with ID and respondents were asked to rate each area as to its relevance on a 5-point Likert-type scale in terms of definite inclusion (5), probable inclusion (4), uncertain (3), probably exclusion (2), and definite exclusion (1). With respect to rating the 1979 items, some topics remained within the top ten priority list in 1999 such as intercourse, venereal disease, pregnancy, inappropriate physical contact, as well as body parts. The items that moved up the top ten priority list were masturbation and rape. In contrast, three items – birth control information, street pickups, and dating – moved out of the top ten priority list.

In 2003, Griffiths and Lunsky published the Socio-Sexual Knowledge and Attitudes Assessment Tool–Revised (SSKAAT-R) which assesses respondents' understanding of relationships, sexuality, and socio-sexual boundaries and attitudes to sexual behaviours. Although the tool requires verbal proficiency, the SSKAAT-R includes pictures in order to maximize communication and comprehension (Wilson et al., 2014). A range of problem scenarios are presented to respondents in order to determine their probable responses (Lunsky et al., 2007). The assessment tool consists of 370 questions covering the following themes: relationships, bodies, and sexuality; knowledge of men's and women's bodies; intimacy, pregnancy, childbirth/childrearing; birth control and sexually transmitted infections; and healthy sexuality and socio-sexual boundaries.

The SSKAAT-R provides a useful and powerful assessment of self-identity (one's own understanding of themselves) by asking respondents to identify photographs of male and female adults, as well as male and female children, which most accurately represent the respondent. It is a tool for adolescents and adults between the ages of 15 and 80. The SSKAAT-R has been described as having good psychometric properties (Blasingame et al., 2014). In field tests in Canada and the United States, the SSKAAT-R was found to have strong internal consistency, test– retest reliability, interrater reliability, and content validity (Lunsky et al., 2007). Specifically, the SSKAAT-R had high Cronbach's alphas (between .81 and .92), suggesting that subscales were assessing related items. Also, the total test-retest correlation was of .96 and the inter-rater agreement was quite high as well (between .89 and .96).

1.2.9 The Need for Revisions to the SSKAAT-R

In a 2016 paper examining the perspective of clinicians on the usefulness and usability of assessment tools, concern was expressed with respect to the current effectiveness of the SSKAAT-R, as well as other tools such as the ASK (Thompson et al., 2016). The age of the sexual knowledge assessment tools was a prominent issue for clinicians, including newer assessment tools barely more than a decade old. For instance, tools such as the SSKAAT-R do not address the recent rise in pornography and internet sexual experiences over the past decade. Given the widespread availability of sexual information and content on the internet, together with the internet's corresponding appeal (e.g., anonymity, portability, and social networking), it is likely that many adolescents learn about sex online (Gonzalez-Ortega et al., 2015). In their study, Gonzalez-Ortega and colleagues (2015) examined the amount of sexual information that a sample of Spanish adolescents received from the internet, along with its usefulness, differences by sex and developmental stage, and associations with sexual behaviour. A total of 3809

secondary students aged 12 to 17 completed a written survey anonymously and a total of 68.4 % of participants reported receiving sexual information online (Gonzalez-Ortega et al., 2015).

Professional knowledge of internet usage among youth with ID is limited, even though research shows that it is an integral part of social life for this group of young people and others (Chadwick et al., 2013; Sobring et al., 2017). Many people with ID live sheltered and socially isolated lives (McVilly et al., 2006) and the internet can then be an important outlet for seeking and maintaining contact with new friends and potential partners (Sobring et al., 2017).

In a study conducted by Löfgren-Mårtenson and colleagues (2018), qualitative interviews were conducted with 17 professionals, 4 males and 13 females, between the ages of 29 and 58. These professionals described challenges with youths' various emotional and intellectual abilities, as well as their technical knowledge in relation to internet use. The results indicated several themes, one being *a two-fold usage*. On the one hand, many young people with ID are socially isolated and the internet can function as their only contact network. The internet is then an important and positive arena for romance and sexuality, and can provide the hope of making new friends and maintaining social relationships. On the other hand, according to the professionals interviewed, the internet can be a negative territory, characterized by bullying, sexual assault, and sexual risks (Löfgren-Mårtenson et al., 2018). They described situations where other actors on the internet took advantage of young people's limited ability to understand internet norms and conduct. This limited ability to understand social norms made them especially vulnerable compared to other young people identified as typical. For example, the group of professionals in the Löfgren-Mårtenson and colleagues' study described situations where youths with ID had been persuaded to undress via web cameras or smart phones under the mistaken belief that they would become popular and acquire new friends and acquaintances without an

intellectual disability. The easy, free, and anonymous access to pornography on the internet, and its influence on young people's views of gender and sexuality, form another potential risk area. When it concerns youths with ID attending special schools, the easy access to pornography is seen as an even more complex and troubling aspect of internet usage because of the difficulty of these youths to understand images of sexuality (Löfgren-Mårtenson et al., 2018).

Given that the SSKAAT-R does not touch upon issues of sexuality related to technological advances and internet accessibility, these would be important elements to consider for the revised version of the tool. Furthermore, with the introduction of new contraceptive methods and different terminology for sexually transmissible infections, other important changes have taken place since the publication of sexual assessment tools and these need to be addressed in a revised version (Thompson et al., 2016). In addition, the SSKAAT-R has been criticized for its largely heteronormative emphasis on sexual behaviour between men and women (Wilson et al., 2014). For instance, individuals who have an ID and who also identify as members of the LGBTQ+ community may not fully be able to relate to certain materials currently included in the tool. The lack of representation of other types of relationships in the tool may also not allow thorough assessment of knowledge and attitudes towards individuals who do not fall in the heteronormative group. Lastly, the SSKAAT-R has been criticized for the length of time required for administration (Ward et al., 2013). Specifically, the administration of the tool typically lasts for a minimum of 1.5 hours and, at times, must be administered in multiple interviews (Ward et al., 2013). Keeping this criticism in mind, it will be important to ask professionals who use the SSKAAT-R if the length of time required for administration is something they view as problematic during their assessment.

Researchers have shown that sex education is not always available for individuals with disabilities (Rohleder & Swartz, 2012), which sustains the dangerous conditions in which individuals remain vulnerable targets for sexual abuse. This vulnerability is due to a lack of understanding regarding appropriate sexual behaviour and inappropriate sexual behaviour (Conod & Servais, 2008). Therefore, the current study is crucial in order to gain an understanding of the most important and urgent areas of challenge for individuals with disabilities regarding their knowledge and attitudes towards sexuality. If we are better able to understand the specific needs of this population, as measured by the SSKAAT-R, we can then modify sex education approaches accordingly and educate people with ID more effectively. Such an accommodated approach is critical for sex education programs. When these programs are individually adapted, they are more likely to increase the ability of individuals with ID to make cognizant and informed decisions about their sexual relationships (Dukes & McGuire, 2009). Additionally, individuals with ID will also be better able to make informed choices with respect to birth control and to avoid sexual abuse (Dukes & McGuire, 2009)

1.3 The Current Study

As part of a larger research project to update the SSKAAT-R, the purpose of the current study was to identity current topics of relevance with respect to sexuality for individuals with ID as well as to examine the strengths and limitations of the SSKAAT-R. This investigation of what needs to be updated or changed in the SSKAAT-R will improve the actual assessment of sexual knowledge and, consequently, identify topics that are more problematic or perhaps of more importance for these individuals. In addition to considering new questions or topics for a revised version of the tool, pictures in the SSKAAT-R that are potentially outdated and no longer useful were examined. Furthermore, as previously mentioned, the SSKAAT-R has been criticized for

its largely heteronormative emphasis on sexual behaviour between men and women as well as the length of time required for administration. In order to address these critiques, participants were asked their opinion on the length of administration as well the maximum amount of time they would like to spend administering the tool. Specifically, during the semi-structured interviews, discussions took place in regards to possible suggestions for including questions that are not primarily related to, or focused on, sexual behaviours that strictly occur between men and women. Lastly, professionals in the field were questioned concerning psychometric issues they may have encountered while scoring the SSKAAT-R.

1.3.1 Research Questions

1. What are the current topics of relevance in the area of sexuality for individuals with intellectual disabilities?
2. What enhancements or changes should be made to the SSKAAT-R in order to best assess the sexual knowledge and attitudes of individuals with intellectual disabilities?

    i. What SSKAAT-R components should stay the same?

1.4 Methodology

The current study replicated the study conducted by Griffiths and Lunsky (1999), which examined the aspects of socio-sexual assessment and education that were considered important for people with ID. As did Griffiths and Lunsky (1999), current users of the SSKAAT-R, including psychologists, clinicians, and staff members who work with individuals with ID, were invited to complete a questionnaire regarding their experiences with this tool as well as what they would like to see in a revised assessment tool. For example, given that it is a measure that includes pictures, participants were asked if particular pictures were problematic and needed updating or if newer and relevant areas of experience and innovation, such as advances in

contraception, needed to be included. Although a replication of the original study, the current study differed from that of Griffiths and Lunsky (1999) in that current users were also invited to participate in a semi-structured interview concerning what aspects of the measure they would like to see revised. This consultation permitted a deeper understanding of the perspectives of current users, which will aid in the creation of a third edition of the SSKAAT-R. Ultimately, the end result will be an evaluative tool more reflective of current sexual issues for persons with disabilities. While part of a larger study, this mixed methods thesis focused on current users' experiences with the SSKAAT-R and the thoughts of professionals in the field in terms of suggestions for revisions for the SSKAAT-3.

1.4.1 Participants

A total of 42 participants including psychologists, clinicians, social workers, and other mental health professionals were recruited for the current study. Participants were recruited using a variety of methods. First, the publishing company of the tool, Stoelting, emailed professionals who had previously purchased the SSKAAT-R with a description of the study and a link to the questionnaire. Second, individual emails were also sent to professionals in the field of sexuality and disability who were cited in a current literature review. Third, an electronic poster with an embedded link to the questionnaire was circulated on social media platforms, including Facebook and Twitter. Lastly, organizations and agencies in mental health and assessment were also contacted and asked to share the questionnaire with those they thought would have insight on the SSKAAT-R. Recruitment efforts are documented and placed in Appendix D.

1.4.2 Questionnaire

The first phase of the current study involved sharing a questionnaire (see Appendix B) with professionals in the field in order to obtain their comments and suggestions with respect to

updating the SSKAAT-R. As the original survey used by Griffiths and Lunsky (1999) was not available to the researcher at this time, the questionnaire used for this study was created by means of deconstructing what was noted in the original study. In addition, questions were based upon the current literature review regarding issues that are important for individuals with ID. Questionnaires were completed online via Google Forms. The questionnaire included twenty-seven questions and informed consent was obtained prior to beginning the questionnaire.

In order to maintain consistency with the 1999 study, a section was formatted on a 5-point Likert scale; as a result, participants had the opportunity to rate their perceived importance of topics of assessment and sexual education for individuals with ID. Some questions were closed-ended such as, "*How do you feel about the SSKAAT-R's length?*" with possible answers being "Should be much shorter", "Should be somewhat shorter", "The length is just right", "Should be somewhat longer", or "Should be much longer". However, an example of a question in which the second part was open-ended is, "*Are there any pictures in the SSKAAT-R that you believe to be confusing, irrelevant, or otherwise unhelpful? Please specify.*" The questionnaire took approximately twenty minutes to complete and all participants had the opportunity to enter a raffle draw for the chance to win a $30 Amazon gift card at the end of the survey.

1.4.3 Semi-structured interviews

On the questionnaire, participants were asked if they would be interested in taking part in the second phase of the study – a semi-structured interview. In this second phase, participants were given the opportunity to expand on their answers from the questionnaire and to add detail with respect to what they think is important to consider when updating the tool. One of the main advantages of a semi-structured interview is that it may be used with both individual and group

interview methods (DiCicco-Bloom & Crabtree 2006). Ten interviews were conducted in total and all but one - which was a group interview, including three participants - were held with one participant at a time. The three participants who requested to complete their interview as a group were from the same agency.

Additionally, one of the main advantages is that the semi-structured interview method has been found to be successful in encouraging reciprocity between the interviewer and participant (Galletta, 2013), enabling the interviewer to improvise follow-up questions based on participants' responses (Hardon et al., 2004, Rubin & Rubin 2005) and also allowing space for participants' individual thoughts (Robert Wood Johnson Foundation, 2008). The semi-structured format was helpful in the current study as many participants often began to speak about questions that the interview had planned for later on in the conversation. Being able to skip back and forth between questions allowed the interview to flow better as well as build rapport with participants. The interviews for this second phase took place over the internet on Zoom (Zoom Video Communications Inc, 2016) in order to accommodate professionals who had busy schedules and to allow for greater geographic representation of participants. In addition, Zoom was used to ensure participants' safety, as data were collected during the COVID-19 global pandemic.

Interviews were conducted by the primary investigator of the present study, a graduate student, and the primary investigator of the larger project. The graduate student interviewer was trained by the larger project investigator. Both interviewers followed a pre-determined set of semi-structured interview questions which are included in Appendix C. Example questions included: "*Do you have any suggestions for improving the size, format, or overall administration of the SSKAAT-R?"* and "*Are there any pictures in the SSKAAT-R that you believe to be*

confusing, irrelevant, or otherwise unhelpful?" The semi-structured interview format allowed for flexibility in terms of the questions asked and the discussion with each participant (Galletta, 2013). As such, the interviewer could prompt participants with particular items or images from the SSKAAT-R, when necessary. All interviews were audio-recorded and transcribed verbatim in order to conduct a content analysis following the interviews.

1.4.4 Ethical Considerations

This study was approved by the Laurentian University Research Ethics Board (REB#6020426), which is in accordance with the Canadian Tri-Council Recommendations for Research with Human Participants (see Appendix A).

1.5 Overview of Thesis Document

As this is a manuscript-based thesis, the current document included two distinct articles. The first article is included in the following chapter and is titled "Socio-Sexual Assessment and Education for Individuals with Intellectual Disabilities: A Twenty- and Forty-Year Comparison". It was written and formatted for submission to the *Journal on Developmental Disabilities*. The article explored and compared changes in priorities of socio-sexual assessment and education for persons with ID. The third chapter included the second article titled "The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised: User Experiences in Order to Inform an Update". This article was formatted for submission to the *Sexuality and Disability* journal. This second article examined the SSKAAT-R specifically and highlighted its strength and limitations according to professionals in the field of ID with experience using the tool. Following these two papers, the fourth and final chapter provided a summary of the findings in each paper, outlined areas for future research, and discussed various clinical and practical implications.

Socio-Sexual Assessment and Education for Individuals with Intellectual Disabilities:

A Twenty- and Forty-Year Comparison

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The current manuscript is formatted for submission to the Journal on Developmental Disabilities (JoDD).

1.1 Abstract

Very little is known about the socio-sexual knowledge and attitudes of adults with intellectual disabilities and tools to measure these constructs are limited. The purpose of the current study was to compare areas of importance in sexual assessment and education for individuals with intellectual disabilities (ID) with those reported approximately twenty (Griffith & Lunsky, 1999) and forty (Wish, et al., 1979) years ago. A total of 42 professionals in the field, including psychologists, clinicians, and staff members who work with individuals with ID completed a questionnaire where they were asked to rate their perceived importance of topics of sexual assessment and education for individuals with ID. Changes in the importance of topics between years are explored and explained in relation to existing literature on issues of sexuality in society, specifically for individuals with ID. In overall ratings, results suggest that some topics remain valued across years such as inappropriate physical contact, intercourse, body parts, and sexually transmitted infections. Certain changes between years appear to reflect a general increase in the acceptance and understanding of the sexuality of individuals with ID. For instance, topics of homosexuality, birth control, and adult movies/literature appear to be of much greater importance in 2020. Limitations and implications of these findings are discussed.

Keywords*:*

Intellectual disability, sexuality, assessment, socio-sexual education.

Socio-Sexual Assessment and Education for Individuals with Intellectual Disabilities: A Twenty- and Forty- Year Comparison

2.2 Introduction

Historically, individuals with intellectual disabilities (ID) were prohibited from taking part in healthy sexual activity. This prohibition of sexual activity was a direct consequence of negative societal opinions and attitudes, which classified individuals with ID as being promiscuous, criminal, or deviant in their sexual behaviours (Di Giulio, 2003; Lumley & Scotti, 2001). In the classic 1927 sterilization case *Buck vs. Bell*, Justin Oliver Wendall Holmes of the United States Supreme Court stated the following, which reflects the prevailing attitude towards the sexuality of individuals with ID at the beginning of the century:

> It is better for all the world if, instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their crime (Hall, 1974, p. 179).

This mindset dominated much of societal thinking into the 1950s, where people with ID lived in segregated settings and were kept away from individuals of the opposite sex (Kempton & Kahn, 1991). It was not until the 1970s that attitudes slowly began to change. The philosophy of normalization was developed, which proposed that the lives of people with ID should follow the normal patterns of the community (Nirje, 1976). As a result of this philosophy, deinstitutionalization and community integration became crucial as policymakers began to deconstruct social structures that had maintained people with disabilities as segregated, unseen, and powerless.

Early sex education programs for individuals with ID were mainly geared towards the control of behaviour and perceived inappropriate sexual activities, such as inappropriate

masturbation (Mitchell et al., 1978). These programs refrained from discussing topics such as dating, relationships, and exploitation (Rowe & Savage, 1987). By the late 1970s, most facilities reported having some type of sex education program; however, sexual activity continued to be frowned upon (Coleman & Murphy, 1980). Institutional staff and educators in the 1970s generally chose to remove explicit conversation of sexual behaviour from sex education reading resources in order to follow the conservative views and attitudes held by staff and parents (Mitchell et al., 1978). Kempton (1975) and Gordon (1971) were some of the first instructors to develop specific programs that provided information not only about sexual biology, but also about other important elements such as relationships, marriage, dating, and parenting.

Socio-sexual education

In the 1980s, many important social changes occurred for individuals with ID. For example, parents of individuals with ID were reportedly less conservative towards sexuality and recognized, in general, the importance of sex education for their children (Johnson & Davies, 1989; Pueschel & Scola, 1988). However, the main focus of sex education at this time was still to discourage individuals with ID from having children and to encourage voluntary sterilization (Rowe & Savage, 1987). Nevertheless, staff members who worked with individuals with ID began to hold more accepting views and attitudes towards sexuality. Specifically, they had a stronger acceptance of sexual behaviour between consenting adults in a private setting (Adam et al., 1982).

The later 1980s and the 1990s included the increasing visibility of sex education programs concerning safe sex and protective behaviours for individuals with ID. These sex education programs were a direct response to the increase in the number of people in society contracting the HIV virus as well as the fear that it may transmit to people with ID, as well as

research identifying the significant number of people with an ID who were experiencing sexual abuse (Turk & Brown, 1993). Needless to say, parents of individuals with ID reported being very afraid that their children were in danger if they were not properly educated on the topic of sexuality.

In the twenty-first century, sexuality was deemed to be a fundamental part of being human (Krebs, 2007; Matich-Maroney et al., 2005). It is now widely recognized that individuals with ID have the same sexuality and intimacy needs and rights as others (Katz & Lazcano-Ponce, 2008; Kijak, 2011; Rushbrooke et al., 2014). In health and social care settings, now more than ever, practitioners are paying attention to issues related to sexuality in terms of their clients' psychosocial supports and education (Greenhill & Whitehead, 2010; Gascoyne et al., 2016; McCann, 2010). In fact, it is now known that the attitudes held by family members and direct care support workers have a profound effect on the ability of individuals with ID to express their sexuality and to make decisions about how to communicate their sexuality (Gilmore & Chambers, 2010; Pebdani, 2016; Pownall et al., 2011; Saxe & Flanagan, 2016).

Nonetheless, the expression of sexuality among people with ID remains a controversial issue (Gomez, 2012; Winges-Yanez, 2014). Despite major policy shifts over the past twenty years – notably, the closure of long-stay institutions and the promise of more socially inclusive models of care and support for individuals with ID – prejudice continues to permeate the issue of sexuality of persons with ID, both in families and in the professional community (Tamas et al., 2019). For example, while the necessity of both effective and appropriate sexual education curricula for those with ID is well established, there exists much debate regarding the availability of empirically-based and appropriately standardized options (Gougeon, 2009). The lack of

empirically based options suggests that sexual education for individuals with ID has been incomplete or even non-existent.

Socio-sexual assessment and the evolution of the SSKAT

In order to tailor relevant and appropriate education programs for individuals with ID, an assessment tool can help gather a better understanding of their specific needs. The Socio-Sexual Knowledge and Attitudes Test (SSKAT; Wish et al., 1979) was the first assessment of sexual knowledge and attitudes designed for individuals with ID and was the most widely employed assessment measure at the time. The SSKAT was developed for individuals who did not have very strong verbal skills and its purpose was to determine what individuals with ID know or think they know about important areas of socio-sexual functioning, as well as their attitudes regarding various sexual practices (Wish et al., 1980). The SSKAT included questions designed to assess both knowledge and attitudes about sexuality with each category being scored independently. Many of the questions on the test were presented with visual aids and often the examinee could respond by pointing to the correct answer. This format allowed the individual to express their knowledge and attitudes in ways that did not rely heavily on verbal skills (Niederbuhl & Morris, 1993).

To create the SSKAT, the authors distributed a questionnaire to 50 parents, educators, and clinicians to help them select items for the test. Participants were asked about their opinions on the importance of different topics for inclusion in assessment and education. Participants were asked to rate each area on a 5-point Likert-type scale in terms of definite inclusion (5), probable inclusion (4), uncertain (3), probable exclusion (2), and definite exclusion (1). Wish et al. (1980) then designed the SSKAT, creating subtest areas within the test. The chosen subtests were judged to be relevant by 75% or more of the participants on the questionnaire. These subtests

included anatomy terminologies, menstruation, dating, marriage, intimacy, intercourse, pregnancy and childrearing, birth control, venereal disease, masturbation, homosexuality, alcohol and drugs, community risks and hazards, and terminology check. The final SSKAT consisted of 208 questions concerning knowledge, 40 questions concerning attitudes, and 13 questions regarding what the examinee thought that they knew about the subtest area.

In 1999, Griffiths and Lunsky distributed the Wish et al. (1979) questionnaire to inform an update of the SSKAT. In total, 80 participants who worked closely with individuals with ID filled out the survey. Once again, participants were asked to rate the relevance of each topic on a 5-point Likert-type scale in terms of definite inclusion (5), probable inclusion (4), uncertain (3), probable exclusion (2), or definite exclusion (1). With respect to rating the 1979 items, some topics remained within the top ten priority list in 1999, such as intercourse, venereal diseases, pregnancy, inappropriate physical contact, and body parts. Items that moved up the top ten priority list included masturbation and rape. In contrast, three items – birth control information, street pickups, and dating – moved out of the top ten priority list. With respect to additional items respondents believed should be included within socio-sexual assessment or training, the most frequently identified item was HIV/AIDs; other health issues and sexually related medical disorders were also requested. One of the other major areas noted for inclusion was sexual abuse and violence, including topics of consent, coercion, and abuse prevention. One of the most important changes to the 1999 measure was that it was no longer considered a test. The Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised (SSKAAT- R) is referred to as an "assessment tool", which is more indicative of its purpose. The original SSKAT also had 14 sections as stated above, but the SSKAAT-R was revised to only include seven subtests:

anatomy; male bodies; female bodies; intimacy; pregnancy, childbirth, and childrearing; birth control and STDs; and healthy sexual boundaries.

Given that the SSKAAT-R was last updated 18 years ago, and considering the documented prejudices against the sexual expression of individuals with ID that still exist today (Dinwoodie et al., 2020; Tamas et al., 2019), and the changing sexual attitudes and awareness of issues, there is a clear need for another revision of the measure to reflect the current socio-sexual education needs of individuals with ID. The current study is a replication of the research conducted by Griffiths and Lunsky (1999) and is part of a larger project aimed at updating the SSKAAT-R. The purpose of the current study was to compare areas of importance in sexual assessment and education for individuals with ID with those reported approximately twenty (Griffith & Lunsky, 1999) and forty (Wish et al., 1979) years ago, respectively.

2.3 Materials and Methods

Ethics approval for the current study was provided by the Laurentian University Research Ethics Board, Ontario, Canada, which is in accordance with the Canadian Tri-Council Recommendations for Research with Human Participants (REB#6020426). Current users of the SSKAAT-R and professionals in the field, including psychologists, clinicians, and staff members who work with individuals with ID were invited to participate in this study.

The study consisted of sharing a questionnaire via the online survey application Google Forms. Participants were recruited using a variety of methods. First, the publishing company of the tool, Stoelting, emailed professionals who had previously purchased the SSKAAT-R with a description of the study and a link to the questionnaire. Second, individual emails were also sent to professionals in the field of sexuality and disability who were cited in a current literature review. Third, an electronic poster with an embedded link to the questionnaire was circulated on

social media platforms, including Facebook and Twitter. Lastly, organizations and agencies in mental health and assessment were also contacted and asked to share the questionnaire with those they thought would have insight on the SSKAAT-R.

The questionnaire was a replication of the survey used in the 1999 study, with revisions that considered the results of an updated literature review. The questionnaire included twenty-seven questions and informed consent was obtained prior to beginning the questionnaire. In order to maintain consistency with the 1999 study, a section was formatted on a 5-point Likert scale; as a result, participants had the opportunity to rate their perceived importance of topics of assessment and sexual education for individuals with ID. These topics included those used in both the 1979 and 1999 studies to capture changes in ratings over time. At the end of the questionnaire, all participants had the opportunity to enter a raffle draw for the chance to win a $30 Amazon gift card.

2.3.1 Participants

The majority of participants identified as being female (83%), white (63%), and heterosexual (68%). For the most part, participants indicated being from the United States (71%) and Canada (27%). Information was also gathered on the participants' places of work. Specifically, respondents most commonly worked in a university or academic setting (33%), private practice (26%), or community agency (17%). Table 1 provides additional information regarding participant demographic characteristics.

Table 1.

Participant Characteristics

Demographic Characteristics	
Gender (n, %)	
Female	35 (83)
Male	7 (17)
Average age (mode, range)	42.9 (42, 24-76)
Ethnicity (n, %)	
White	26 (63)
Other[a]	15 (37)
Sexuality (n, %)	
Heterosexual	28 (68)
Gay	4 (10)
Bisexual	3 (7)
Lesbian	2 (5)
Asexual	2 (5)
Other[b]	2 (5)
Geographic Location (n, %)	
United States	29 (71)
Canada	11 (27)
Europe	1 (2)
Work Setting (n, %)	
University or academic	14 (33)
Private practice	11 (26)
Community agency	7 (17)
Hospital	3 (7)
Government	3 (7)
Research	2 (5)
Non-profit	1 (3)
Average years in the field (mode, range)	17.8 (5, 2-50)

Note: Other self-reported ethnicities included: Jewish; Canadian; European; Euro-American; Eastern European Ashenazi; American Indian Caucasian; Irish-Swedish American; White British; English; Hispanic; Non-Hispanic; Celtic; and North African.
[b]Other self-reported sexualities included: pansexual and heteroflexible.

2.3.2 Data Organization and Analysis

Once collected, questionnaire data were imported into Microsoft Excel for exploratory analysis. For the purpose of the current study, the data from two sections of the questionnaire were analyzed: *Rate your perceived importance of the following topics for assessment and sexual education of individuals with intellectual disabilities* and *Are there specific topics that you believe should be added to a revised version of the SSKAAT-R?* Analysis was conducted largely through descriptive statistics. In order to analyze responses from the first section, the percentages associated with participant ratings were calculated for each topic. Then, a two-sample z-score for the difference between proportions was used to calculate significance values, identifying any

significant differences between years. Percentages were also used to list and compare the current top ten topics of importance to the ones reported in previous years. In terms of analysis for the second section, all responses that mentioned identical topics were tallied to calculate the associated percentages of participants mentioning a given topic.

2.4 Results

Participant characteristics are previously provided in Table 1. In the current study, 42 participants responded to the questionnaire. The 2020 results were compared to the 1999 and the 1979 results using a two-sample z-score for difference between proportions (see Table 2 for the comparison of 1979 and 2020 and Table 3 for the comparison of 1999 and 2020). As was the case in the 1999 study, the current study examined differences in ratings for the "definite inclusion" criterion. Specifically, Table 2 and Table 3 compare what participants believed should definitely be included in assessment and education in the years 1979, 1999, and 2020. An alpha of .05 was considered to indicate a significant difference between years.

2.4.1 Changes in priority between 1979 and 2020

Comparing 1979 and 2020, three topics produced significant downward change results, meaning that they were less endorsed now than in the past: marital procedures/responsibilities, childrearing, and hitchhiking. These topics were endorsed by participants significantly less in 2020 than in 1979 in terms of "definite inclusion" in assessment and education. On the other hand, only one topic demonstrated a significant upward trend towards definite inclusion: adult movies and literature (see Table 2 for a detailed analysis).

Table 2.
Importance of Socio-Sexual Items for Assessment and Education in 1979 and 2020

Item	Definitely Important/ Total Response (%)		*Z* Score and Significance Levels
	2020	1979	
Body Parts	35/42 (83%)	37/50 (74%)	NS
Masturbation	33/42 (59%)	32/50 (64%)	NS
Premarital Sexual Contact/Limits	18/41 (44%)	35/49 (70%)	NS
Birth Control			NS
Information	36/42 (86%)	42/50 (84%)	
Services	36/42 (86%)	37/50 (74%)	NS
Sexually Transmitted Infections	31/42 (74%)		
How to Catch		43/50 (84%)	NS
Symptoms		43/50 (84%)	NS
Whom to tell		43/50 (84%)	NS
Intercourse	36/42 (86%)	43/50 (84%)	NS
Childbirth	22/42 (52%)	26/49 (53%)	NS
Homosexuality	36/42 (86%)	27/49 (54%)	NS
Incest & Inappropriate Sexual Contact	37/42 (88%)	33/50 (66%)	NS
Extramarital Contact/Limits	12/41 (29%)	22/48 (44%)	NS
Inappropriate Physical Contact	40/42 (95%)	41/50 (82%)	NS
Marital Procedures & Responsibilities	9/42 (21%)	32/50 (40%)	Z=-4.09 p=<.00001
Childrearing	15/42 (36%)	28/50 (56%)	Z=-3.48 p=.00048
Alcohol	20/41 (49%)	22/49 (44%)	NS
Drugs			NS
Medication	18/41 (44%)	27/50 (54%)	
Marijuana	18/41 (44%)	26/50 (52%)	NS
Hard drugs	18/41 (44%)	25/49 (50%)	NS
Street Pickups	21/42 (50%)	40/50 (80%)	NS
Hitchhiking	10/41 (24%)	35/50 (70%)	Z=-4.33 p=<.00001
Adult movies & Literature	28/42 (67%)	14/50 (28%)	Z=371 p=.0002
Cursing	5/41 (12%)	14/49 (28%)	NS
Nudity/Exposure	32/42 (76%)	31/50 (48%)	NS
Voyeurism	24/41 (59%)	24/50 (48%)	NS
Suggestibility to dares	22/42 (52%)	35/50 (70%)	NS
Dating	35/42 (83%)	37/50 (74%)	NS
Going steady	20/42 (48%)	24/50 (48%)	NS
Engagement	16/42 (38%)	24/50 (48%)	NS

Note: NS = Not significant

2.4.2 Changes in priority between 1999 and 2020

Looking at changes between 1999 and 2020, marital procedures/responsibilities and hitchhiking also remain significantly less endorsed. In addition to these two topics, masturbation, sexually transmitted infections, extramarital contact/limits, cursing, going steady, and engagement were all endorsed significantly less in 2020 than they were in 1999. However, three topics generated significant upward change results, meaning that they were significantly more endorsed now than in the past: birth control (services), homosexuality, and adult movies/literature (see Table 3 for a detailed analysis).

Table 3.
Importance of Socio-Sexual Items for Assessment and Education in 1999 and 2020

Item	**Definitely Important/ Total Response (%)**		***Z* Score and Significance Levels**
	2020	**1999**	
Body Parts	35/42 (83%)	75/80 (93.8%)	NS
Masturbation	33/42 (79%)	77/80 (96.2%)	Z=-3.12 p=.002
Premarital Sexual Contact/Limits	18/41 (44%)	48/78 (60%)	NS
Birth Control	36/42 (86%)		
Information		69/80 (86.2%)	NS
Services		54/79 (76.5%)	Z=2.08 p=.04
Sexually Transmitted Infections	31/42 (74%)		
How to Catch		72/80 (90%)	Z=-2.34 p=.02
Symptoms		71/80 (88.8%)	Z=-2.12 p=.03
Whom to tell		72/80 (90%)	Z=-2.34 p=.02
Intercourse	36/42 (86%)	73/80 (91.2%)	NS
Childbirth	22/42 (52%)	48/80 (60%)	NS
Homosexuality	36/42 (86%)	55/80 (68.8%)	Z=2.05 p=.04
Incest & Inappropriate Sexual Contact	37/42 (88%)	68/80 (85%)	NS
Extramarital Contact/Limits	12/41 (29%)	45/79 (56.2%)	Z=-2.88 p=.004
Inappropriate Physical Contact	40/42 (95%)	70/80 (87.5%)	NS
Marital Procedures & Responsibilities	9/42 (21%)	36/79 (45%)	Z=-2.62 p=.009
Childrearing	15/42 (36%)	37/78 (46.2%)	NS
Alcohol	20/41 (49%)	38/77 (47.5%)	NS
Drugs	18/41 (44%)		
Medication		41/79 (51.2%)	NS
Marijuana		37/79 (46.2%)	NS
Hard drugs		37/79 (46.2%)	NS
Street Pickups	21/42 (50%)	45/76 (56.2%)	NS

Hitchhiking	10/41 (24%)	50/78 (62.5%)	Z=-4.12 p=<.00001
Adult Movies & Literature	28/42 (67%)	33/79 (41.2%)	Z=2.61 p=.009
Cursing	5/41 (12%)	25/77 (31.2%)	Z=-2.41p=.02
Nudity/Exposure	32/42 (76%)	52/80 (65%)	NS
Voyeurism	24/41 (59%)	37/78 (46.2%)	NS
Suggestibility to Dares	22/42 (52%)	47/76 (58.8%)	NS
Dating	35/42 (83%)	69/80 (86.2%)	NS
Going steady	20/42 (48%)	62/80 (77.5%)	Z=-3.34 p=.0008
Engagement	16/42 (38%)	49/80 (61.2%)	Z=-2.44 p=.01

Note: NS= Not significant

2.4.3 Major shifts in overall ratings of definite inclusion

With respect to overall ratings in all three time periods, some topics remained valued and important across the years. For example, inappropriate physical contact, intercourse, body parts, and sexually transmitted infections remained on the top ten priority list in 2020, as they were in 1999 and 1979. However, there were a few considerable and important shifts when examining all three lists (see Table 4).

Table 4.
Top 10 Priority in Socio-Sexual Assessment in 2020, 1999, and 1979

	2020	1999	1979
1	Inappropriate Physical Contact (95%)	Masturbation (96.2%)	Birth Control Information (84%)
2	Incest and Inappropriate Sexual Contact (88%)	Body Parts (93.8%)	Intercourse (84%)
3	Intercourse (86%)	Intercourse (91.2%)	Venereal Disease – How to Catch (84%)
4	Homosexuality (86%)	Venereal Disease – How to Catch (90%)	Venereal Disease – Symptoms (84%)
5	Birth Control (86%)	Venereal Disease – Whom to Tell (90%)	Venereal Disease – Whom to Tell (84%)
6	Dating (83%)	Pregnancy – How to Prevent (90%)	Pregnancy – How to Get (84%)
7	Body Parts (83%)	Venereal Disease – Symptoms (88.8%)	Pregnancy – How to Prevent (84%)
8	Nudity/Exposure (76%)	Pregnancy – How to Get (87.5%)	Inappropriate Physical Contact (82%)
9	Sexually Transmitted Infections (74%)	Rape (87%)	Street Pickups (80%)
10	Adult Movies/Literature (67%)	Inappropriate Physical Contact (87.5%)	Dating (74%) and Body Parts (74%)

For example, the topic of inappropriate physical contact had risen to the top spot of priority in 2020, whereas it was number ten in 1999 and number eight in 1979. Incest and inappropriate sexual contact were ranked as the second most important topic whereas it did not even make the list in the previous years. In addition, homosexuality, birth control, nudity/exposure, and adult movies/literature appear to be of much greater importance in 2020.

In addition to rating the items, participants were asked in an open-ended question to share any additional topics they believed should be included in a socio-sexual assessment, such as the SSKAAT-R. The most frequently identified other topic was online sexuality or sex over the internet. Approximately 33% of participants highlighted the desire to see questions added to socio-sexual assessments regarding online safety and boundaries for individuals with ID. When asked about any additional topics that should be added to a revised assessment tool, one participant described:

> Online issues, dating apps, Facebook, etc., as ways individuals might connect in healthy or unhealthy/exploitative ways. Maybe this could be a subsection in relevant subtests that could be scored/included or excluded depending upon the needs of the individual and his/her access to such means of communication without having to throw out the whole subtest if those topics are not relevant.

Furthermore, a subset of participants (~30%) communicated the need for more emphasis on gender and sexual diversity. Issues related to individuals who identify as LGBTQ+ and the request for less of a reliance on rigid views of sexual and gender identity were important for many respondents. In response to the open-ended question – *Are there specific topics that you believe should be added to a revised version of the SSKAAT-R?* – one participant wrote, “From my understanding, there needs to be more in terms of sexual and gender diversity. For example,

"men's" and "women's" bodies feels like an outdated way to speak about gendered embodiment." Another participant shared, "We must complicate the dichotomy of women/men bodies a bit more. I supported many people with I/DD who cross dress, are in lesbian relationships or are less hetero- and more fluid in their sexuality and/or asexual or are supported by families/parents who are LGBTQ."

Although online sexuality and sexual and gender diversity were the two most frequently reported areas of interest in terms of topics that should be added to socio-sexual assessment, consent was another topic that was often mentioned. Roughly 19% of participants reported wanting more content on the topic of informed consent. The topic of consent is touched upon in the current version of the SSKAAT-R; however, participants requested more information with respect to the awareness of the ability to revoke consent, as well as recognizing and responding to consent or revocations of consent. One participant shared, "(…) how it is freely given, reversible, enthusiastic and specific." Overall, these findings, gathered from the comparison of years and open-ended responses, provided a glimpse into what sort of content should be emphasized in a revised assessment tool for individuals with ID.

2.5 Discussion

As part of a larger project aimed to update the SSKAAT-R, the goal of the current study was to compare the areas of importance in sexual assessment and education for individuals with ID with those reported approximately twenty (Griffith & Lunsky, 1999) and forty (Wish et al., 1979) years ago. Data were collected by sharing a questionnaire with professionals in the field of disability and/or sexuality in order to obtain their thoughts on topics of sexuality.

2.5.1 2020 vs. 1979

The results comparing significant differences between the years 2020 and 1979 are not entirely surprising. The significant upward importance of adult movies and literature in 2020 reflects the ubiquity and easy access to this type of content (Braithwaite et al., 2015), which was not the case in 1979. As there was no internet at this time, pornographic magazines and other printed texts were the most common iterations of "adult content". However, approximately 94% of households in Canada now have internet access (Statistics Canada, 2019), with 93% of young people online and ''sex'' as the most frequently researched topic (Braun-Courville & Rojas, 2008).

Certainly, because of technological advances, such as the appearance of smartphones and increased internet accessibility over the last 20 years alone, it is not surprising that this is an area strongly supported for inclusion in socio-sexual assessment and education. Indeed, researchers have reported that an increasing number of young people with ID are using the internet for learning and entertainment (Feng et al., 2008). Normand and Sallafranque-St-Louis (2016) suggested that, as with most of the population, a growing proportion of young people with ID use the internet and that their numbers will rise with the development of increasingly user-friendly sites for people with low levels of literacy. Furthermore, specific risk factors associated with sexual solicitation on the internet (e.g., lack of sexual knowledge, social isolation) also apply to individuals with ID (Normand & Sallafranque-St-Louis, 2016).

In 2020, significantly less importance was placed on marital procedures/responsibilities, childrearing, and hitchhiking than in 1979. Marital procedures and accompanying responsibilities were significantly less endorsed today, which could speak to the fact that society, as a whole, has slowly shifted to the belief that marriage may not be as important or a necessity in order to have

sexual relations (Eze, 2014). In the 1970s, marriage was, for most, a lifetime contract. At the time, divorce was expensive and infrequent, and the production of "illegitimate" children was stigmatized (Lundberg et al., 2016). More and more, couples are deciding to have children before marriage (Perelli-Harris et al., 2012), do not get married at all (Rontos et al., 2017), and/or hold much more flexible views of this traditional form of union (Carlson & Berger, 2020). It has been suggested that the institution of marriage, in general, is becoming an outmoded institution which has been decoupled from the childbearing process (Perelli-Harris et al., 2017). The attitudes held by the general population regarding marriage may, in fact, hold true for individuals with ID who have been shown to be less likely to marry (Beber & Biswas, 2009). The latter may be an indication explaining why this topic is significantly less endorsed today for assessment and education for individuals with ID.

With respect to parent perceptions regarding the romantic relationships of their adult children with ID, most parents strongly opposed the possibility that their child's relationship could lead to marriage and, possibly, parenthood (Neuman, 2020). From the perspective of individuals with ID, however, researchers have indicated that people with ID are open to marriage (Box & Shawe, 2014) and think that marriage is important (Healy et al., 2009). The finding in the current study suggests that although individuals with ID have the desire for more serious commitment and marriage, some of society's attitudes and beliefs are, at best, anachronistic and, at worst, prejudicial.

Interestingly, the current study reported that childrearing is deemed significantly less important for individuals with ID now than it was in 1979. This finding is surprising given research elsewhere suggesting that women with ID are now accessing pregnancy-related services more than before (Homeyard et al., 2016; Brown et al., 2017). Of course, historically low

childbearing rates in this population because of involuntary institutionalization and sterilization speak to patriarchy and prejudice rather than the views of women with ID. Recent data from Ontario, Canada have demonstrated a general fertility rate of 20.3 livebirths per 1000 women with ID in contrast with 43.4 per 1000 in women without ID (Brown et al., 2016). Women with ID are also nearly twice as likely as those without ID to give birth to another child within a year of first delivery (Brown et al., 2018)and experience higher rates of pregnancy complications compared to women without ID. In brief, available research on individuals with ID becoming pregnant and having children would suggest that this topic is an area worth exploring for socio-sexual assessment and education.

2.5.2 2020 vs. 1999

When comparing the current results with those reported in 1999, adult movies/literature, homosexuality, and birth control (services) are all areas of greater consequence. The rise in importance of homosexuality and birth control may demonstrate a general recognition and acceptance of sexuality that may be more fluid for people with ID (Byers et al., 2013; Hellemans et al., 2010). In essence, these findings may demonstrate the acceptance of areas of gender and sexuality that could be encountered by individuals with ID, just as they are by people without ID. In further support of this finding, which was noted in the ranking of topics, participants also expressed the desire for an emphasis on sexual diversity in the open-ended portion of the survey asking about new topics that should be added.

With that said, it is important to note the potential biases of the current sample, as these are participants with experience working in the field of ID. As such, attitudes may very well differ from those of the general population (Jones & Magowan, 2010). Researchers in the twenty-first century are, indeed, beginning to explore issues specific to people with ID who

identify as LGBTQ+. For example, researchers have suggested an increased diversity of gender identities and sexual orientations among individuals with autism spectrum disorder (ASD) compared to populations without ASD (e.g., George & Stokes, 2018; Pecora et al., 2020).

Furthermore, literature suggests that individuals with ID whom are also gay, lesbian, or bisexual often times experience prejudice and harassment which, in turn, frequently leads to a double stigma associated with their disability and sexual orientation (Duke, 2011; Meyer, 2003) Hall (2010) reported that this prejudice and discrimination may create further marginalization and social exclusion and limit the opportunity for developing relationships. In the current study, the increased awareness of issues for individuals with ID who also identify as gay was also well demonstrated by the increased importance of this topic on the top ten priority list. Specifically, homosexually was rated fourth in overall importance for inclusion in assessment and education for individuals with ID in 2020.

In total, eight topics were rated as significantly less important today when compared to the results of 1999: marital procedures/responsibilities, hitchhiking, masturbation, sexually transmitted infections, extramarital contact/limits, cursing, going steady, and engagement. The fact that marital procedures/responsibilities and hitchhiking continue to be significantly less important in 2020 when compared to 1999 may demonstrate its current inappropriateness or unsuitability in education and assessment. In other words, such continuing trends would suggest that hitchhiking and marital procedures/responsibilities are topics that are not suitable to include in assessment today.

Other items, such as cursing and “going steady” also seem to be quite outdated and less relevant today. The concept of “cursing” is not directly linked to sexuality by nature and the expression “going steady” is an outdated one, meaning “(…) continuous dating of the same

person over an extended period to the exclusion of all other persons" (Autumn, 1960, p. 239). Although the topic of dating may be crucial in the development of sex education programs for people with ID (Healy et al., 2009; Heifetz et al., 2020), the terminology "going steady" may have been what persuaded participants to identify this item for "definite inclusion" significantly less often than in the past. Specifically, meeting and getting to know someone are now most popularly done online and through dating applications (Rosenfield & Thomas, 2012), and the language used to refer to dating and being in a relationship has shifted over time. For example, in contrast to "going steady", "dating" and "hooking up" are common terms that refer to a variety of sexual behaviours, ranging from kissing and touching to forms of sexual intercourse with no expectation of emotional connection or future contact between partners (Bradshaw et al., 2010).

Other topics significantly less endorsed in 2020, such as sexually transmitted infections (STIs), are perhaps more surprising to note. In the general population, STIs are a significant public health concern (Government of Canada, 2019). In fact, the rates of reported chlamydia, gonorrhea, and infectious syphilis have increased significantly over the past decade. Between 2008 and 2017, the rates of chlamydia increased by 39%, gonorrhea by 109%, and infectious syphilis by an alarming 167% (Government of Canada, 2017). In terms of individuals with a disability, researchers have shown that sexually active youth with ID are at a higher risk for contracting STIs compared to individuals without ID (Baines et al., 2018; Mandell et al., 2008). Engaging in unprotected sex, having multiple sexual partners, a history of STIs, sexual abuse, and alcohol and drug use are all risk factors for contracting STIs (Mayo Clinic, 2021). Unfortunately, people with disabilities are also at an increased risk for many of these additional risk factors (Mayo Clinic, 2021).

In addition, Dekker, Safi, Van der Zon, Echteld, and Evenhuis (2014) reported a lack of knowledge among young people with ID regarding the mechanism of sexual intercourse and contraceptive methods. This lack of knowledge leaves adolescents with ID at a greater risk and vulnerability to STIs in comparison to adolescents without ID. Given research on STIs more broadly, as well as the potential risks for individuals with ID, one might have been led to believe that the topic would not decrease in importance over the years. With that said, in terms of the overall ratings, STIs do remain on the top ten priority list in the current year, which indicates that the topic is still of relevance and should still be included in socio-sexual assessment and education for individuals with ID.

2.6 Limitations and Considerations

This study does have a few limitations that are important to note. First, not all of the topics covered in the 1999 study were included. Specifically, only twenty-five of the twenty-eight topics studied in the 1999 study were included. Although individuals may have mentioned these topics in open ended sections, topics of rape, marriage, and pregnancy were not available as options to rate in this study.

Second, the sample size of the current study was smaller than anticipated. As this study was a replication of the 1999 study, the current sample of 42 participants fell short of the number of people that participated in the earlier study which had a total of 80. The sample size was smaller than anticipated, in part due to recruitment challenges during COVID-19. However, the current study was complemented by a series of interviews to further contextualize findings reported. Undoubtedly, researchers will also have the opportunity to continue collecting data in order to address some of the gaps that were noted in the current study.

2.7 Conclusion

The results of the present study highlighted current topics of importance that should be considered for inclusion in socio-sexual assessment and education for individuals with ID. The results obtained in the present study were compared with those reported approximately twenty (Griffith & Lunsky, 1999) and forty (Wish et al., 1979) years ago in order to note changes that occurred between generations. As Griffths and Lunsky (1999) reported in their study, certain changes between years appear to reflect a general increase in the acceptance and understanding of the sexuality of individuals with ID. It is encouraging to see topics such as homosexuality and birth control getting more recognition now as a point of discussion for individuals with ID. Other topics that were shown to be less important today demonstrate the fact that beliefs and priorities are different now than they were forty and even twenty years ago and reflect attitudinal and societal change over time. The results of the current study present perceived areas of current need, according to professionals in the field of ID and sexuality, in terms of topics to be included in an updated version of the SSKAAT-R. Furthermore, the identification of topics that are more and less important in 2020 is a significant step towards creating an assessment tool that is more reflective of current times and issues of sexuality for people with ID. As such, education programs can be developed based upon more recent research which, simultaneously, can address the current lack of empirically-based options for sex education among this population.

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Key messages from this article

People with disabilities: It is important that you can learn about how to have good romantic and sexual relationships with other people. People who work with individuals with disabilities think certain topics are really important to learn about.

Professionals: Professionals and service providers need to be educated on the implications of incomplete socio-sexual education and are encouraged to use an assessment tool such as the SSKAAT-R in order to tailor more specialized and individualized education programs.

Policy Makers: Policy Makers need to also be educated on the implications of incomplete socio-sexual education and ensuring that individuals with intellectual disabilities have access to assessment and education to best meet their need.

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The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised: User Experiences in Order to Inform an Update

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3.1 Abstract

The purpose of this paper was to examine the strengths and limitations of the Socio-Sexual Knowledge Assessment Tool – Revised in order to inform the development of a revision of the tool. This study implemented a two-phase, sequential explanatory mixed methods approach. In the first phase, a total of 19 professionals in the field having prior experience administering the SSKAAT-R completed an online questionnaire, where they were asked to share their thoughts on the strengths, weaknesses, and needed improvements of the tool. The second phase consisted of a semi-structured interview with participants who wanted to expand on their responses and provide additional details. A total of 12 participants took part in an interview. Results indicated that the main strengths of the SSKAAT-R include the pictures and visually presented information, its comprehensiveness, its ease of use, its attitude items, as well as the fact that it may help in the developmental of targeted intervention programs for individuals with ID. On the other hand, reported limitations of the SSKAAT-R included the outdated pictures and the lack of information regarding sexual and gender minorities as well as how to navigate the internet safely. As researchers look to update the tool, the findings from this study will be useful in creating a version that is more representative of current issues of sexuality and that is more user-friendly.

Keywords:

Intellectual disability, sexuality, sexual knowledge, assessment, Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised.

The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised: User Experiences in Order to Inform an Update

3.2 Introduction

It has been well established that individuals with intellectual disabilities (ID) demonstrate lower levels of sexual knowledge than people in the general population, as well as people with physical disabilities [1,2, 3]. Unfortunately, deficits in sexual knowledge may place individuals with ID at a higher risk for sexual exploitation and abuse, as well as deprive them of opportunities to develop meaningful intimate relationships [4]. Given the possible consequences of limited knowledge, sexual knowledge assessment tools may be used by clinicians to identify gaps in knowledge for this population [5, 9]. In fact, research into the sexual knowledge of individuals with ID has resulted in the development of several sexual knowledge assessment tools, including the *Human Relations and Sexuality Knowledge and Awareness Assessment* [6], the *SexKen-ID* [7], the *General Sexual Knowledge Questionnaire* [8], the *Assessment of Sexual Knowledge* [9], and the *Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised* [10], which play a crucial role in determining who would benefit from sex education and what that education should focus on [5, 11, 12]. For instance, the use of a sexual knowledge assessment tool with an individual with ID may uncover specific deficits in knowledge on methods and use of birth control and these areas may be taught and reviewed through an individualized program. With that said, assessment tools can get outdated as topics of importance in sexuality may change or evolve over time [13]. As part of a larger project aimed at updating the SSKAAT-R, the goal of the present paper was to examine the strengths and limitations of the tool as reported by current users of the SSKAAT-R.

The Socio-Sexual Knowledge and Attitudes Test

In 1980, the *Socio-Sexual Knowledge and Attitudes Test* (SSKAT) was published. The SSKAT was based on research carried out in the 1970s with men and women labelled with an ID living in institutions and in the community, and was the first assessment of sexual knowledge and attitudes designed specifically for individuals with ID. It was the most widely employed assessment measure at the time. Its original content was determined by distributing a survey to parents, educators, and institutional and community-based clinicians regarding the importance of various areas for assessment and education. At the time, the most important areas for sex education included birth control information, intercourse, venereal disease (how to catch, symptoms, and who to tell), and pregnancy (how to get and prevent). In addition, avoiding street pickups and inappropriate physical contact were also ranked as very important. The identification of body parts and dating were also considered important at the time.

The Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised

More than 20 years after the development of the SSKAT, the assessment tool was updated by Griffiths and Lunsky [10] to address subtle but crucial changes in priorities for socio-sexual assessment and education [13]. The revised measure, called the *Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised* (SSKAAT-R), was designed to assist educators and clinicians working with people with ID. In brief, it evaluates information that persons with ID have about their bodies, socio-sexual intimacy, relationships, and issues of abuse. The SSKAAT-R assists clinicians in uncovering information that can be used in conjunction with other clinical interviews and assessment strategies. The revised 2003 version brought forward many important changes such as the

measure no longer being considered a test. Rather, the updated measure was referred to as an "assessment tool", which was more indicative of its purpose. The original SSKAT had fourteen sections but the SSKAAT-R was simplified to only include seven subtests: anatomy; male bodies; female bodies; intimacy; pregnancy, childbirth, and childrearing; birth control and sexually transmitted infections; and healthy sexual boundaries.

Based on research conducted by Griffiths and Lunsky [13], the SSKAAT-R provided educators and clinicians with a more relevant assessment measure, which touched upon issues of sexuality that were more current for individuals with ID at the time. The SSKAAT-R may be used to uncover and understand gaps in knowledge when there seems to be an apparent issue of sexuality. To elaborate, Thompson and colleagues [15] found that when professionals were asked why they would use a sexual knowledge assessment measure, there was a consensus among clinicians that the sexual health of people with ID is generally only investigated if there is a “problem”, such as public masturbation, alleged sexual abuse, or other sexualized behaviours.

The SSKAAT-R was designed for use with adolescents and adults between the ages of 15 and 80. The SSKAAT-R has been described as having good psychometric properties [10]; moreover, field tests in Canada and the United States determined that the SSKAAT-R had strong internal consistency, test–retest reliability, interrater reliability, and content validity [10]. The SSKAAT-R was developed with the following goals [10]:

- Determine the knowledge and attitudes of people with developmental disabilities with respect to socio-sexual information;
- Serve as a baseline and an educational aid when developing person-centered socio-sexual curricula;
- Provide a means of evaluating socio-sexual training effectiveness;

- Aid in evaluation research; and
- Serve as one aspect of a comprehensive assessment for individuals who may be experiencing socio-sexual challenges. (p. 1)

In terms of the SSKAAT-R materials, the kit includes a manual, a pack of 20 record forms, a set of stimulus cards, an easel picture book, as well as a training video. When purchasing the kit, all materials come packed in a plastic briefcase that can be used to carry the tool to different settings. The SSKAAT-R itself is administered using the easel picture book, which can be folded upwards and is placed between the examiner and the examinee. For administration convenience, each subscale is separated by a tab, extending from the side of the easel. The easel picture book is designed so that the side facing the examinee typically shows an illustration or a multitude of illustrations and the examiner's side contains a bolded script and corresponding prompts that should be read verbatim. The SSKAAT-R also gives scoring instructions on the examiner's side of the easel, so there is no need to refer to the manual during the assessment [10].

On the easel are a combination of photographs and sketches. The authors opted to utilize sketches for private sexual activities, recognizing that photographing someone engaged in such activities would be an invasion of their privacy. Activities that are considered to be less private are captured through photographs when possible. With respect to the types of questions included in the tool, some SSKAAT-R items require a response of "yes" or "no", some require the selection of a picture or drawing from three or four choices, and other items require a verbal description or explanation. It is worth noting that the attitude items are recorded for information only and are not scored as "correct" or "incorrect". These questions are worded so that the individual with ID can indicate if a particular behaviour is "OK" or "NOT OK" in their opinion

[10]. For example, one attitude-based question is: “What do you think about two women doing that (kissing) on a first date? Is it OK or NOT OK? What about after lots of dates? What about if they are married?”. Another example of an attitude-based question is: “What do you think about people getting married? Is it OK or NOT OK?”

The SSKAAT-R should only be administered when there is a specific purpose that will benefit the individual with ID, such as the assessment of knowledge for educational purposes or as part of a clinical evaluation. The individual with ID must provide consent and must be fully aware of both the reason for administration and what will be done with the information. The SSKAAT-R can be used as a full assessment battery or to evaluate specific areas of knowledge or attitudes [10]. Because it is not a standardized test, individual subscales can be administered separately. The SSKAAT-R can also be used in combination with other measures or clinical observations to assist clinicians working with individuals who have experienced socio-sexual difficulties.

In addition to its clinical utility, the SSKAAT-R has also been used for research purposes. For example, using the normative data set of people with ID from the development of the SSKAAT-R, Lunsky and colleagues [16] compared two subgroups of sexual offenders with ID and examined whether they differed from matched non-offenders on sexual knowledge. Elsewhere, authors have used the SSKAAT-R to examine sexual knowledge in individuals with ID before and after a sex education program [17, 18].

Current Study

Given that the SSKAAT-R was last updated approximately eighteen years ago, there is a clear need for another revision of the tool to reflect the current socio-sexual needs of individuals with ID. In addition, the SSKAAT-R has faced some critiques over the years that need to be

addressed. Notably, although the SSKAAT-R integrated heterosexual and homosexual relationships into one category, there are still critiques that there is a heteronormative bias [19]. For instance, individuals who have an ID and who also identify as members of the LGBTQ+ community might not be able to relate to particular photographs or situations described in the tool. The lack of representation of other types of relationships in the tool also may not allow thorough assessment of knowledge and attitudes towards individuals who do not fall in the heteronormative group. Additionally, the SSKAAT-R has been criticized for the length of time required for administration and the need to administer the tool in multiple interviews [20]. Lastly, the SSKAAT-R does not address the recent rise in pornography and internet sexual experiences over the past decade [21]. Given the widespread availability of sexual information and content on the internet, together with the internet's corresponding appeal (e.g., anonymity, portability, and social networking), it is likely that many adolescents learn about sex online [22]. The latter are critiques that need to be explored and considered for future assessment revisions.

As part of a larger project aimed at updating the SSKAAT-R, the purpose of the current study was to determine the strengths and limitations of the SSKAAT-R, as well as to inform the development of a revision of the tool. The present study was an in-depth analysis of strengths, weaknesses, and recommended improvements according to clinicians with prior experience using the SSKAAT-R.

3.3 Materials and Methods

This study implemented a two-phase, sequential explanatory mixed methods approach [23]. Ethics approval for the current study was provided by the Laurentian University Research Ethics Board, Ontario, Canada, which is in accordance with the Canadian Tri-Council Recommendations for research with human participants (REB#6020426). Current users of the

SSKAAT-R including professionals in the field, psychologists, clinicians, and staff members who work with individuals with ID, were invited to participate in this study. Phase I of the current study was a replication of the research conducted by Griffiths and Lunsky [13] and Phase II involved semi-structured interviews with professionals in the field.

3.3.1 Phase I

Phase I was completed by sharing a questionnaire via the online survey application Google Forms. Participants were recruited using a variety of methods between November 2019 and June 2020. Specifically, the publishing company of the tool, Stoelting, emailed professionals who had previously purchased the SSKAAT-R with a description of the study and a link to the questionnaire. Individual emails were also sent to professionals in the field of sexuality and disability who were cited in a current literature review. An electronic poster with a link to the questionnaire was also posted on social media platforms, including Facebook and Twitter. In addition, agencies working in the field of disabilities were contacted via email and asked to share the questionnaire with anyone they thought would have knowledge and experience with the SSKAAT-R.

The questionnaire used for the current study was a replication of the survey conducted by Griffiths and Lunsky [13] and included several revisions that considered the results of an updated literature review. Specifically, a portion of the survey was replicated from the 1999 survey, which allowed participants to rate specifics topics of sociosexual assessment and education on a 5-point Likert scale. Other portions of the current survey, such as questions regarding thoughts on the length and pictures of the SSKAAT-R, were added to address more up-to-date concerns and critiques. In total, the questionnaire included twenty-seven questions and informed consent was obtained prior to beginning the questionnaire. At the end of the questionnaire, all

participants had the opportunity to enter a raffle draw for the chance to win a $30 Amazon gift card.

3.3.2 Phase II

All participants who completed the questionnaire were invited to participate in Phase II. The interviews for this second phase took place over the internet on Zoom [24] in order to accommodate professionals who had busy schedules and to allow for greater geographic representation of participants. In addition, Zoom was used to ensure participants' safety, as data were collected during the COVID-19 global pandemic. With participant consent, all interviews were recorded via Zoom to allow for transcription afterwards. The interviews lasted between thirty minutes and one hour depending upon the depth and breadth of information participants chose to share.

Interviews were conducted by the primary investigator of the present study, a graduate student (KG), as well as the primary investigator of the larger project (SW). The graduate student interviewer was trained by the larger project investigator. Both interviewers followed a pre-determined set of semi-structured interview questions. Example questions included: "*Do you have any suggestions for improving the size, format, or overall administration of the SSKAAT-R?"* and "*Are there any pictures in the SSKAAT-R that you believe to be confusing, irrelevant, or otherwise unhelpful?"* The semi-structured interview format allowed for flexibility in terms of the questions asked and the discussion that ensued with each specific individual [25]. Specifically, the interviewer could prompt participants with particular items or images from the SSKAAT-R, when necessary. For example, following asking the previously stated question regarding the pictures in the SSKAAT-R, the interviewer could prompt the participant by

showing a picture that had already been flagged as problematic in the questionnaire portion of the study.

3.3.3 Participants

A total of 19 individuals reported having previous experience with the SSKAAT-R when completing the online questionnaire portion of the study. The majority of participants identified as being female (84%), white (68%), and heterosexual (74%). Additionally, the majority of participants indicated being from the United States (47%) and Canada (47%). Information was also gathered on the participants' places of work. Specifically, respondents indicated most commonly working in a university or academic setting (32%), private practice (21%), community agency (16%), or government setting (16%). Table 1 provides additional information regarding participant demographic characteristics for the questionnaires.

Table 1.
Questionnaire Participant Characteristics

Demographic Characteristics	
Gender (n, %)	
Female	16 (84)
Male	3 (16)
Average Age (mode, range)	42.8 (39, 26-69)
Ethnicity (n, %)	
White	13 (68)
Other[a]	6 (32)
Sexuality (n, %)	
Heterosexual	14 (74)
Other[b]	5 (26)
Geographic Location (n, %)	
United States	9 (47)
Canada	9 (47)
Europe	1 (6)
Work Setting (n, %)	
University or Academic	6 (32)
Private Practice	4 (21)
Community Agency	3 (16)
Government	3 (16)
Hospital	2 (10)
State Facility	1 (5)
Average years in the field (mode, range)	16.5 (5, 3-40)

Note: [a]Other self-reported ethnicities included: European; Hispanic; Jewish; Non-Hispanic; Irish-Swedish American; and Celtic.
[b]Other self-reported sexuality included: bisexual and lesbian.

Of the 19 participants who completed the questionnaire and indicated having prior experience with the SSKAAT-R, 12 participants agreed to take part in Phase II (see table 2 for additional participant demographic characteristics for this phase). A total of 10 interviews were conducted and all but one - which was a group interview, including three participants - were held with one participant at a time. The three participants who took part in the group interview all worked in the same agency. With respect to familiarity with the SSKAAT-R, 50% of participants who took part in an interview indicated using the tool at least once a year, 25% of participants used the tool regularly (e.g., monthly), and another 25% indicated using the tool only occasionally.

Table 2.
Interview participant characteristics

Demographic Characteristics	
Gender (n, %)	
Female	11 (92)
Male	1 (8)
Average Age (mode, range)	40.3 (28, 26-69)
Ethnicity (n, %)	
White	8 (67)
Other[a]	4 (33)
Sexuality (n, %)	
Heterosexual	9 (75)
Other[b]	3 (25)
Geographic Location (n, %)	
Canada	7 (59)
United States	4 (33)
Europe	1 (8)
Work Setting (n, %)	
University or Academic	6 (50)
Government	4 (34)
Community Agency	1 (8)
Private Practice	1 (8)
Average years in the field (mode, range)	17.3 (10, 3-40)

Note:
[a]Other self-reported ethnicities included: Jewish; and European.
[b]Other self-reported sexualities included: bisexual and lesbian.

3.3.4 Data Organization and Analysis

For the purpose of the current study, the descriptive information was derived from two specific questions on the questionnaire: "*In your opinion, what are the strengths of the SSKAAT-R? Please specify."* and "*In your opinion, what are the weaknesses of the SSKAAT-R? Please specify."* All responses that mentioned the same strength or weakness were tallied to calculate the associated percentages of participants mentioning a given topic. This approach allowed for a comparison to be made with respect to areas in the SSKAAT-R that are most in need of change or updating, according to professionals in field of ID.

Next, the analysis of data collected in Phase II began with the verbatim transcription of the interviews and included features such as laughing, pausing, and other audible observations. All identifiable information associated with the participants was removed or changed. For example, pseudonyms were used in the transcripts when participant names were mentioned. Once the transcriptions were finalized, a content analysis approach [26] was employed. Content analysis is a coding and categorizing approach used for exploring large texts in order to determine trends and patterns, their frequency, their relationships, and the structures and discourses of communication [27].

First, *preparation of the data* was achieved by being immersed in it, becoming familiar with it, and obtaining the sense of the whole [26]. Second, the *organization of the data* was achieved by using open coding as well as creating categories and subcategories of the information presented [26]. Specifically, for the current study, responses from the interview transcripts as a whole were read many times over for familiarization purposes; also, the frequency with which a specific answer was provided in the transcripts was noted. For example, as the primary investigator noticed the reoccurring finding of the SSKAAT-R's pictures being out of date and unclear, all similar responses that mentioned pictures being problematic were grouped together and counted. This approach allowed for a keen understanding of responses shared by participants as well as the number of participants who held a similar or identical opinion. Next, the merging of the mixed methods data was completed in a sequential manner. To elaborate, the findings of the qualitative phase of the mixed methods study provided context for the findings of the quantitative phase. Integration through *building* occurred in the present study, as results from one data collection procedure informed the data collection approach of the other procedure, the latter building on the former [28]. The section that follows presents the results of

the study. Reported strengths of the tool are stated first and reported limitations are presented second. The most often talked about strengths and limitations mentioned in the questionnaire are presented with their associated percentages. Following the findings from the quantitative portion, findings gathered from the interviews are also presented to build upon the quantitative results.

3.4 Results

The following results include reported strengths and limitations of the SSKAAT-R with consideration to both questionnaire and interview data.

3.4.1 Reported Strengths of the SSKAAT-R

In total, 67% of participants stated being impressed with and liking the tool. Also, over half (57%) of questionnaire participants believed it is the appropriate length. Several strengths were also noted by particpants. First and foremost, the pictures and visual aspects of the SSKAAT-R were the most often talked about strength of the tool. Specifically, approximately 31% of participants who answered the question "*In your opinion, what are the strengths of the SSKAAT-R?"* mentioned appreciation of the pictures and the fact that the respondents have access to visual content in order to assist them in answering questions.

Pictures were elaborated upon as a strength in 90% of the interviews. Many interviewed participants mentioned that they appreciated the use of both illustrations and photographs included in the tool. For example, one participant stated the following when deliberating upon the use of both illustrations and pictures of real people: "I do think it's a strength. I think the ones where it's possible to have real images… I think that's preferred, but, one thing I have found in my research is that folks report that they don't want to see super intimate pictures of real-life individuals."

The comprehensiveness of the SSKAAT-R was another important strength reported by participants in the current study. Approximately 21% of participants who filled out the questionnaire indicated liking the fact that the SSKAAT-R touches upon a wide variety of topics related to sexuality, such as body parts, pregnancy, menstruation, sexually transmitted infections, healthy boundaries, and relationships. To further build on this finding, 70% of interviewees reported appreciating its thoroughness. For example, when referring to the SSKAAT-R as a whole, one participant shared: "This one I would think is the most comprehensive. It kind of touches a lot of bases." Another participant said: "I did like the whole variety. I like the fact that it covers so many different topics that…I think, it's just so important."

In addition to the pictures and the overall comprehensiveness of the SSKAAT-R, other strengths mentioned by participants in the questionnaire included its ease of use (15%) and the fact that it can help in the development of targeted interventions for individuals with ID (15%). Indeed, some participants reported their belief that the SSKAAT-R is user-friendly in both phases of the current study. Building upon the questionnaire findings, 40% of the interviews included mention of the tool as relatively easy to learn and administer. Furthermore, many interviewees identified using the tool to help tailor education programs for their clients. For example, one participant stated: "The SSKAAT is primarily used when we're trying to identify what the client's current knowledge base is and determine what specific education and further service we can provide them from there." 50% of interviewees also mentioned the fact that the SSKAAT-R does speak to *some* sexual minority relationships. For example, the SSKAAT-R does depict relationships between two women and two men. The simple fact that there is talk of non-heterosexual relationships and attitudes in the SSKAAT-R was considered a definite strength for participants, especially considering that the tool was created in 2003.

Finally, it should be noted that half (50%) of interviewed participants emphasized the importance of having a tool that considers assessment of both knowledge and attitudes, although this finding was not reflected in the questionnaire responses. One interview participant said:

> Looking at the attitude portion and seeing where they stand on it (sexuality), it helps us address our clinical support of maybe it's not just knowledge the person needs, but that self-esteem and comfort and support from an LGBTQ perspective. So, I appreciate the attitudes portion a lot particularly with someone who is struggling with that part of their identity.

3.4.2 Reported Limitations and Areas for Improvement on the SSKAAT-R

Several areas of improvement were identified in both questionnaire and interview responses. In fact, when given the chance to expand on areas where the SSKAAT-R should be improved, 90% of interviewees stated that safety issues for individuals with ID needed improvement with respect to online dating, social media, online pornography, and the sharing of information and pictures over the internet. One participant's response underscored the importance of having a tool that is able to assess knowledge on internet safety precautions: "One of the biggest referrals that I get recently is around internet issues. So, watching inappropriate stuff on the internet or contacting people inappropriately on the internet ... and that's just not captured. There's nothing in there about that." Another participant suggested that not only should technology and sexuality issues be added to a revised version, but that these issues should receive a separate classification on the tool: "I definitely think it's important. And people are meeting people differently these days. They're starting relationships on the internet. So, yes, I think there probably does need to be an overall internet safety section."

Although the inclusion of a range of relationships was mentioned as a strength in the SSKAAT-R, there was still further room for improvement, particularly with regard to recognizing a broader spectrum in terms of gender, as well as broadening sexual orientations beyond simply homosexual and heterosexual. Specifically, 26% of questionnaire participants shared their opinion that the SSKAAT-R is too focused on heteronormative relationships and should further address other sexual orientations and gender identities. Interview results also provided clear endorsement of stronger inclusivity towards sexual minorities and issues specific to the LGBTQ+ community. One participant shared:

> I think looking at it today… one area has to do with just sort of gender versus sexuality. So, I think there's an increased recognition that people with developmental disabilities like everyone else have a wide spectrum of sexual orientation and gender representations. So, the fact that it again tends to focus on heterosexual and homosexual…It's definitely an area that needs improvement.

The use of pictures constituted a topic that was reported as a strength, but also in need of improvements. Indeed, as previously mentioned, the pictures and visual aspects of the SSKAAT-R were the most frequently reported strength. However, when asked about areas where the SSKAAT-R may fall short, some questionnaire participants stated that the pictures are largely outdated and, at times, unclear. When specifically asked for their opinions of the pictures in the tool, approximately 33% of respondents reported wanting an overall updating of pictures in terms of color and clarity. During one interview, a participant shared: "It's so old! It's just so old. In the same breath as saying the pictures are helpful, (…) they are very dark and a lot of them are very unclear". In fact, 40% of interviewees also highlighted that the pictures are outdated and, as a result, they represented a considerable weakness of the SSKAAT-R for professionals in the

field. For instance, when given the opportunity to identify specific pictures which have been flagged as problematic during their practice with the SSKAAT-R, participants identified the picture of a mother burping her baby, the pictures of birth control methods, the location laminates, and the illustration of pornography.

Lastly, when asked about possibly problematic questions on the SSKAAT-R in the questionnaire, approximately 1/3 of respondents did not thing there were any. Even so, several respondents identified questions about cancer as being problematic. They were said to be quite confusing and perhaps too abstract for the individuals being assessed. Specifically, it was reported that some individuals with ID have difficulty with the question with respect to the prostate-specific antigen (PSA) test. When talking about possible issues of the tool, one participant stated the following regarding the PSA test: "I don't remember which section it's in, but it's this random question about cancer and it feels very out of place, like, it just got put kind of in the middle there and, quite honestly, before I started doing this assessment, I had no idea what the answers were myself." Another participant stated: "Some of the breast exam and prostate exam stuff… a lot of the time, they didn't get that one. Yeah, so, I don't know if maybe that one needs to be a little more clarified or removed even." In brief, the results of the current study provided an overview of what should remain the same and what must be considered for updates in a revised version of the SSKAAT-R.

3.5 Discussion

The current study was conducted as part of a larger project aimed at updating the SSKAAT-R. The goal of this specific paper was to pinpoint the strengths, limitations, and areas in need of improvement on the SSKAAT-R according to professionals working in the field of disability and/or sexuality who have prior experience with it. Overall, the mixed methods

findings indicated that many aspects of the SSKAAT-R are appreciated although some areas, such as the pictures as well as the lack of information regarding internet safety and sexual minorities, were highlighted. The key strengths, limitations, and areas for improvement are discussed.

3.5.1 Strengths of the SSKAAT-R

Overall, reactions to the SSKAAT-R were positive. Many questionnaire participants indicated being impressed with the tool (68%), holding the opinion that the length is just right (57%), and that there are no problematic terms (50%) or questions (43%) that need to be addressed. Nevertheless, it is not surprising that many participants indicated approval of the SSKAAT-R given that, in its time, the previous version of the tool (i.e., the SSKAT) was the most widely employed measure of sexual knowledge and attitudes for individuals with ID [29]. What is perhaps more interesting to note is that over half of questionnaire participants believed the length of the tool was not too long nor too short. Indeed, many participants in this study thought that the length was perfect, although the SSKAAT-R has previously been criticized for the length of time required for its administration [20]. Correspondingly, there were still 31% of questionnaire participants who thought the SSKAAT-R's length should be reduced. This finding confirms, to some extent, what has been suggested in the literature, that some professionals in the field who are using the tool are struggling with its length [20]. While the length of the tool seems to be an issue for at least a few participants, the results of this study also revealed that one of the main components of the SSKAAT-R that is well-liked and appreciated is its comprehensiveness.

With respect to the comprehensiveness of the SSKAAT-R, 21% of questionnaire participants reported this factor as a significant strength of the tool. This finding, which was also supported in the semi-structured interviews, suggests that having a tool that covers a wide variety

of topics pertaining to sexuality is an important factor for professionals who use the SSKAAT-R. Indeed, when one considers other sexual knowledge assessment tools, such as the *Sexual knowledge, experience and needs scale for people with intellectual disability (SexKen-ID)*, the *General Sexual Knowledge Questionnaire (GSKQ)*, the *Sexual Knowledge and Behaviour Assessment Tool (SKABAT)*, the *Human Relations and Sexuality Knowledge and Awareness Assessment: for People with an Intellectual Disability (HRSKAAP-ID*), and the *Assessment of Sexual Knowledge (ASK)*, it has been reported that the SSKAAT-R and the ASK cover the most components of sexual health in sexual knowledge [30].

Indeed, according to Thompson and colleagues [30], the SSKAAT-R and the ASK both cover 19 (66%) out of a possible 29 components of sexuality. In addition, it has been previously reported by Watson [18] that one of the greatest strengths of the SSKAAT-R is the breadth of the information assessed. The SSKAAT-R not only examines surface questions and issues (e.g., defining menstruation), but provides more practical questions (e.g., asking how often a woman should change a sanitary pad and addressing the topic of menopause). If the SSKAAT-R is being administered for the purpose of assessing what the individual needs to learn about sexuality, it is reported as useful in identifying tangible areas of weakness or strength for a given individual [18]. Given this previous research, it is understandable that the SSKAAT-R's comprehensiveness repeatedly came up as a strength in the current study. In addition, it is possible that participants appreciated having the opportunity to collect detailed information that would help them in their specific field of work. For instance, many participants reported working in an academic (33%) or private practice (26%) setting which speaks to the versatility of the tool.

In addition to the SSKAAT-R being comprehensive, participants in the current study highlighted the pictures as a significant strength of the tool. This finding may suggest that

professionals and clinicians appreciate that individuals with lower levels of verbal ability may also take part in the assessment [10]. As researchers have shown, some individuals with ID struggle with communication and conveying messages to others [31, 32]. Indeed, individuals with ID may experience difficulties in understanding spoken, signed, or written language and/or expressively sharing messages [31, 32]. That said, providing pictures and visual aids has been reported as an effective way to communicate with some individuals with ID [33] and explains, at least in part, why participants in the current study may have appreciated the inclusion of pictures in the SSKAAT-R. Additionally, Thompson and colleagues [30] reported in their study that, when compared to other assessment tools of sexual knowledge, the SSKAAT-R is the only measure that depicts both a diversity in sexual orientation and cultural groups in its pictures. The finding that the SSKAAT-R is the only tool depicting such diversity may be another explanation as to why participants in the current study stated that the pictures were a strength, even as they often expressed a need to expand on different sexual orientations and gender identities.

Next, the finding that participants enjoyed the SSKAAT-R because they found it easy to use and administer is encouraging given that a goal for a revised version of the tool is to make it even more user-friendly. With that said, this finding is not entirely surprising given that the previous version of the tool, the SSKAT, was generally rated by users as easy to score and graph [10]. In addition to the reported ease of scoring of the SSKAT, it was also described as easy to follow and administer in terms of its structure. However, it had been suggested that questions and stimulus pictures should be combined into an easel-type display for ease of use [10]. Also, it was suggested that questions in the SSKAT should be included in the Record Form [10]. As these suggestions were, in fact, addressed and added accordingly within the earlier revisions to the SSKAAT-R, it speaks to why participants in the current study liked the format and thought

the scoring and administration were simple to follow. Additionally, the SSKAAT-R has very good psychometric properties. The tool is reported to have good internal consistency, high inter-rater reliability, and high test-retest reliability [10]. The clear and straightforward instructions of the SSKAAT-R may lead to an increased reliability of the tool and, ultimately, a more valid assessment.

Finally, participants in the current study highlighted their enjoyment of the SSKAAT-R because it effectively supports the development of individualized interventions and education programs for individuals with ID. Of course, this finding is rather expected as one of the main reasons the SSKAAT-R was developed was "to serve as a baseline and an educational aid when developing person centered socio-sexual training effectiveness" [10, p.1]. With that said, it is encouraging to note that the data in the current study indicated that the SSKAAT-R is indeed being used for one of its intended purposes. In addition, half of the interview participants shared their appreciation that the SSKAAT-R not only looks at knowledge but attitudes as well. The admiration for the attitude-based questions was an important finding given that the previous version was criticized for its attitudes section and the way in which it scored questions as "correct" or "incorrect" [10]. Chrastina and Vecerova [34] confirmed that the nature and extent of support required by individuals with ID can only be established by assessing their sexual knowledge as well as their attitudes. Thus, assessing attitudes remains an important and relevant component in supporting individuals with ID.

3.5.2 Limitations of the SSKAAT-R

Despite the number of strengths of the SSKAAT-R discussed by participants in this study, there were also several limitations and suggestions for improvement. Undoubtedly, issues with respect to internet safety and online dating are more prevalent now than ever [35]. Internet

access can offer many benefits to people with ID, such as learning, social interaction, and inclusion in mutual support groups [36]. However, some risks have also been identified for those who are perceived as especially vulnerable to abuse, including people with ID [37]. Some of the identified risks associated with internet use include unwanted contacts (e.g., sexual harassment, cyberbullying, or abuse of personal and private information) and inappropriate behaviour of the individual with ID (e.g., insulting or threatening others) [38]. With that said, there are no sexual knowledge assessment tools for individuals with ID that currently address sexual issues with respect to technology.

Specifically, sexting or other issues related to internet safety are not covered in the SSKAAT-R, the SexKen-ID, the GSKQ, the SKABAT, the HRSKAAP-ID, or the ASK [30]. The lack of inclusion of these issues may become quite problematic given that high-risk internet behaviours, such as unwanted sexual solicitation, unwanted exposure to sexual material, and creation of provocative social network profiles, have been reported for many adolescents [39 - 42]. Also, several studies on people with ID have highlighted possibly risky situations during internet use, especially on social networking sites [36, 43 - 44]. Taking into consideration the increased accessibility of the internet and the risks associated with internet use for individuals with ID, it is understandable that participants in the current study felt that these topics deserved robust treatment in the SSKAAT-R. This step forward would help to better support individuals with ID by addressing gaps in their knowledge in terms of how the internet works, how to use it properly, and how to navigate its potential dangers.

Many participants thought that the SSKAAT-R was presently lacking in terms of information related to diversity in gender identity and sexual orientation. This finding suggests that the current version of the SSKAAT-R does not cover enough questions with respect to the

knowledge and attitudes held towards the LGBTQ+ community. Issues pertaining to individuals in the LGBTQ+ community seems to be an important area of assessment for clinicians who work with individuals with ID as it was articulated by many questionnaire participants and over half of interviewees. Indeed, individuals who identify as LGBTQ+ and who are diagnosed with ID desire romantic and sexual connections [45]. A number of factors, however, have been identified as barriers to sexual expression and to the health and well-being that youth with ID face [46]. For example, caregivers and service providers demonstrate discomfort with the sexual and gender identities of LGBTQ+ youth with ID as well as with their sexual and romantic relationships [45]. Furthermore, researchers have suggested that individuals with ID who are also gay, lesbian, or bisexual often experience prejudice and harassment which, in turn, frequently leads to a double stigma associated with their disability and sexual orientation [47 – 48]. All in all, the findings from the current study may demonstrate a general acceptance by professionals in supporting individuals with ID in a more inclusive manner. The findings from the current study also demonstrate a clear need for additional questions on the SSKAAT-R with respect to issues which may be encountered by individuals identifying as LGBTQ+ and diagnosed with ID, specifically.

The pictures on the SSKAAT-R were another area of concern for many participants. Presently, the pictures in the SSKAAT-R are black and white and these were critiqued as being too dark for respondents to clearly see and understand in quite a few instances. Many participants thought or suggested that the pictures need replacement or revision, using more current cameras as well as capturing images which are more relatable to the present. The concern that the SSKAAT-R's pictures are not clear enough is an important finding, given that the co-occurrence of intellectual and visual impairment is not uncommon [49 -50]. In fact, Splunder and colleagues [50] reported that 14% of the adult population with ID has a visual impairment. It may very well

be for this reason that participants were worried about the clarity of the images in the SSKAAT-R. With that said, another possible reason for the reported concern regarding picture quality and clarity may stem from the fact that many individuals with ID have difficulty with recognizing and interpreting emotions [51]. Some of the illustrations of people in the SSKAAT-R may be too dark and unclear for these individuals to interpret what they are feeling. This difficulty is a real issue as it is crucial that the individuals being assessed clearly see the discomfort or pain some people are depicting when engaging in an unwanted sexual act.

With respect to the specific pictures that were highlighted as problematic, many participants thought that the picture of birth control methods was outdated and needed some revisions. The SSKAAT-R does not mention the use of intrauterine devices (IUDs), which have become a very popular method of birth control in the last decade [52]. In fact, more women in the United States use an IUD than ever before, approximately 4.4 million [53]. In Canada, intrauterine contraceptives should be offered as a first-time method of contraception to women, according to The Society of Obstetricians and Gynaecologists of Canada [54]. Another example of a picture in the SSKAAT-R which was reported as problematic was the illustration depicting pornography. The image in the SSKAAT-R is of pornographic magazines, which may appear like normal magazines or books to individuals with ID. Unlike in the past, when pornography was mostly found in then-conventional forms of magazines, books, and films, the internet has become the main method for the distribution of pornography [55]. The rise of internet pornography is presumably because of the increased anonymity, affordability, and accessibility that it provides [56 – 58]. Therefore, internet pornography should be considered for a revised picture of pornography in a new version of the SSKAAT-R. Overall, the reported strengths and limitations of the SSKAAT-R are not enterally surprising considering the time that has elapsed

since its last update. However, the findings from the current study provide information on the specific thoughts of professionals which will be useful when creating an updated version of the tool.

3.6 Limitations and Considerations

The current study has a few limitations that are important to consider when looking at the findings. First, the sample size was small for both questionnaires and interviews. Specifically, the strengths and limitations of the SSKAAT-R reported in the current study may not have encompassed or been fully representative of the majority of clinicians who use the tool. It is possible that other clinicians and professionals may have different thoughts on the tool which were not captured in this study. Furthermore, another limitation was that some participants who filled out the questionnaire had minimal previous experience with the SSKAAT-R. It is possible that those participants who had used the SSKAAT-R infrequently (once or twice in their lives) did not fully remember the details of the tool while answering the questionnaire. Also, the lack of familiarity with the tool may have prevented a thorough analysis and critique of its parts. However, 75% of the sample did report using the tool a least monthly or yearly indicating that the majority had some familiarity with the SSKAAT-R.

3.7 Conclusion

The results of the present study underscore many strengths and limitations of the SSKAAT-R for individuals with ID. In essence, the current study served as a critique of the tool and exposed what seems to be working and what may need adjustments, according to professionals in the field of sexuality and/or disability. As researchers look to revise this assessment tool in the future, the findings from this study may well be beneficial in creating a tool that is more representative of current issues of sexuality that is more user-friendly for those

administering it. Although reactions to SSKAAT-R have generally been positive throughout the literature, the tool has previously been criticized for its largely heteronormative emphasis on sexual behaviour between men and women, the length of time required for its administration, and for the fact that it does not address the recent rise in pornography and sexuality over the internet. Indeed, these were all concerns which were brought forward and confirmed by participants in the current study. However, many participants thought that its current comprehensiveness was important and indispensable, even given, for some, the untenable length of the tool. Elsewhere, although the pictures and visual aspects were the most reported strengths of the tool, they were also criticized for being outdated and unclear. On the whole, the current study's findings are a significant step forward in the development of a sexual knowledge assessment tool that is more reflective of present times, accessible and usable for both examinees and examiners, and of greater service to those with intellectual disabilities.

Declarations:

I, K. Gessie, declare that this paper, and the research to which it refers, is the product of my own work.

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Authors' contribution:

K. Gessie developed the research question, acquired the data, conducted the data analysis, and wrote the majority of the article.

S. L. Watson and K. D. Harding were the Master's supervisors supporting the primary investigator (K. Gessie) and provided extensive feedback and revisions for the article.

Y. Lunsky was the Master's committee member and provided extensive feedback and revisions for for the article.

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Chapter 4: Conclusion

As part of a larger project intended to update the SSKAAT-R, the goals of this thesis were to identify what enhancements or changes should be made to the SSKAAT-R and to identify the current topics of relevance in the area of sexuality for individuals with ID. The intent was to discover what needs to be updated, changed, or remain the same in the SSKAAT-R in order to improve the assessment of sexual knowledge for individuals with ID. In this fourth and final chapter, the results from the two papers are briefly summarized and presented in terms of the research questions stated in chapter one. Also, the findings will be discussed in relation to the larger body of literature. The chapter finishes with suggestions for future research and clinical implications.

4.1 Summary of Paper 1

Researchers have demonstrated that the expression of sexuality in persons with ID remains a controversial topic of discussion (Gomez, 2012; Winges-Yanez, 2014). Although there have been significant policy shifts over the past twenty years - such as the closure of long-stay institutions - prejudice continues to exist with respect to the sexuality of persons with ID, both in families and in the professional community (Tamas et al., 2019). For instance, while the necessity of effective and appropriate sexual education curricula for those with ID is well established and documented, the availability of empirically-based and appropriately standardized options has previously come into question (Gougeon, 2009). Given this reported lack of consistency in the field, it becomes imperative to develop educational programs for individuals with ID using an assessment tool that is current and up-to-date (McCabe, 1993).

The first paper titled “Socio-Sexual Assessment and Education for Individuals with Intellectual Disabilities: A Twenty- and Forty-Year Comparison” replicated research conducted

by Griffiths and Lunsky (1999) to compare current topics of importance in sexual assessment and education with those reported approximately twenty (Griffiths & Lunsky, 1999) and forty (Wish et al., 1979) years ago. In this paper, the goal was to investigate what professionals in the field believe is important in the domain of sexuality for individuals with ID to answer one of the two research questions stated at the outset of this thesis project: *What are the current topics of relevance in the area of sexuality for individuals with ID*? According to the participants who took part in this study, the following topics were reported as most important in 2020: inappropriate physical contact, incest and inappropriate sexual contact, intercourse, homosexuality, birth control, dating, body parts, nudity/exposure, sexually transmitted infections, and adult movies/literature. These topics are particularly important to note as some of them were reported as significantly more or less important today when compared to previous years (1979 and 1999). The fact that priorities seem to have changed means that current socio-sexual assessment and education programs for individuals with ID may be examining components of sexuality that are no longer relevant in the present day. Subsequently, individuals with ID may not be provided with the most relevant assessments and services. In fact, topics that may currently be covered such as marital procedures/responsibility, hitchhiking, and going steady were reported as out of date in the current study and should be considered for removal or changes in order to best meet the needs of individuals with ID.

As was demonstrated in this first paper, major shifts have occurred in terms of topics that are considered important for socio-sexual assessment and education for persons with ID. For example, when comparing the results of the current paper with those reported in 1999, adult movies/literature, homosexuality, and birth control (services) are all areas which were reported as more important today. Indeed, there may very well be many reasons explaining why priorities

change over time. First and foremost, certain historical moments - such as deinstitutionalization - had a large impact on people's thoughts and attitudes towards persons with disabilities (Antonak & Livneh 1995; Burge et al., 2007). All of a sudden, persons with ID were encouraged to engage in the community instead of experiencing separation in an institutional setting. People with ID became visible. Indeed, the inclusion of individuals with ID back into their homes and into community settings slowly started to change the perception of others towards them. As attitudes towards individuals with ID began to change, priorities for socio-sexual education did as well.

To elaborate, one might take note of the current emphasis on the importance of addressing the topic of homosexuality. Indeed, the topic was rated as significantly more important to include in assessment and education today than in the past. The finding that homosexuality is a topic of relevance today may demonstrate a general recognition and acceptance of the fluidity of sexuality for people with ID (Byers et al., 2013; Hellemans et al., 2010). Generally speaking, attitudes with regard to homosexuality in the 1970s were not as accepting as they are now. The often-cited 70 percent who believed that sexual relations between two individuals of the same gender was wrong remained remarkably consistent between 1973 and 1991 (Yang, 1997). In fact, homosexuality had just recently been removed as a mental disorder in the *Diagnostic and Statistical Manual,* which speaks to how sexual orientation was viewed during the time when the original SSKAT was created (Mendelson, 2003). In 1999, however, homosexuality became of larger importance for inclusion in assessment and education for persons with ID (Griffiths & Lunsky, 1999), which reflects shifts in attitudes and societal changes. In 2020, the topic rose to the fourth most important topic for inclusion.

Furthermore, birth control (services) was reported as significantly more important in 2020 when compared to previous years. Once again, this finding may speak to a considerable

shift in the acceptance of individuals with ID having control over their bodies and sexual health. With that said, reproductive health care for women with ID has a controversial and, until relatively recently, negative history. Enforced sterilizations and institutionalization with strict segregation of the sexes were strong features of twentieth century approaches (Kempton & Kahn, 1991). Thankfully, such overtly eugenic practices have largely ceased, although managing the fertility of women with ID remains problematic because issues around choice and control still remain prominent (Dotson et al., 2003). With that said, given higher fertility rates in young women with ID, accessible information on sexual health and contraception should be a greater part of educational and community-based programs for young persons with ID in order to prevent unplanned pregnancies (Brown et al., 2016).

4.2 Summary of Paper 2

It has been established that individuals with ID demonstrate lower levels of sexual knowledge than people in the general population and those with physical disabilities (Galea et al., 2004; McCabe, 1999). Unfortunately, deficits in sexual knowledge may place individuals with ID at a greater risk for sexual exploitation and abuse as well as deprive them of opportunities to develop meaningful and healthy intimate relationships (Azzopardi-Lane & Callus, 2014). Given the potential consequences of limited knowledge – and in order to effectively support individuals with ID with respect to sexuality issues – sexual knowledge assessment tools may be used by clinicians to identify gaps in knowledge for this population (Buttler, 2003). In effect, some authors propose that such assessment tools should be used to identify gaps in the sexual knowledge of people with ID and, furthermore, these authors recommend that identified gaps should be addressed through individually tailored sexual health education programs (Bell & Cameron, 2003; Galea et al., 2004; Garwood & McCabe, 2000).

Supporting this proposition are several studies that have utilized pre- and post-sexual knowledge assessments to demonstrate an increase in the sexual knowledge of people with ID following a sexual health education intervention (Dukes & McGuire, 2009; Murphy et al., 2007; Wells et al., 2012).

The SSKAAT-R is unique. Not only does it measure knowledge, but it includes many items related to attitudes where a respondent may indicate approval or disapproval of various sexual behaviours. In the SSKAAT-R, attitudes are addressed separately and do not receive any score at all. The authors of the SSKAAT-R felt that attitudes are very personal and cannot, therefore, be judged right or wrong (Griffiths & Lunsky, 2003). Attitude responses are simply recorded as "OK" or "NOT OK" and are addressed separately from knowledge scores. Consequently, if one wanted simply to use the SSKAAT-R to determine an individual's attitudes toward particular areas of sexuality, this would be possible. This area seems to continue to be of importance as it was highly appreciated by many clinicians interviewed in the current study.

With that said, the SSKAAT-R was last updated eighteen years ago and there is a clear need for another revision of the tool that reflects the current socio-sexual needs of individuals with ID. In addition, the SSKAAT-R has received some criticism over the years which needs to be addressed and evaluated. For example, the SSKAAT-R has been criticized for its largely heteronormative emphasis on sexual behaviour between men and women (Wilson et al., 2014). Additionally, the SSKAAT-R has been criticized for the length of time required for administration (Ward et al., 2013). Specifically, the administration of the tool typically lasts for a minimum of 1.5 hours and, at times, requires multiple interviews (Ward et al., 2013). Lastly, the SSKAAT-R does not address the recent rise in pornography and internet sexual experiences over the past decade (Hald et al., 2013). The goal of the second paper, titled “The Socio-Sexual

Knowledge and Attitudes Assessment Tool- Revised: User Experiences in Order to Inform an Update", was to identify the strengths and limitations of the SSKAAT-R. The second paper aimed to answer the second research question of the current thesis: *What enhancements or changes should be made to the SSKAAT-R in order to best assess the sexual knowledge and attitudes of individuals with intellectual disabilities?*

In fact, the findings from this second study brought to light many strengths and weaknesses of the SSKAAT-R. First, the pictures and visual aspect of the SSKAAT-R were very often reported as an important strength for participants. The finding that many participants liked the visual aspect suggests that professionals and clinicians should remain cognizant of the fact that individuals with lower levels of verbal ability may also take part in the assessment. In a recent article published by Thompson and colleagues (2018), a model for assessment was proposed in order to accommodate individuals with ID during an assessment. In this model, a four-stage cycle of planning, administration, evaluation and reporting was introduced. One of the main accommodations in the administration phase of the cycle emphasized the communication domain. The authors suggested using a visual schedule, providing examinees with a break card to request a break, using nonverbal subtests, simplified instruction, and allowing the examinee to point rather than verbalize responses (Thompson et al., 2018). The results of the current study confirm that it is indeed crucial to use a tool (such as the SSKAAT-R) that provides a visual aspect for the respondents.

The comprehensiveness of the tool was another area appreciated by participants. Many participants thought that the SSKAAT-R was able to assess a wide range of issues related to sexuality. In effect, the breadth of information assessed was a significant strength for participants. Furthermore, many participants highlighted the fact that the SSKAAT-R was an

accessible tool or easy to learn and administer. It was also reported that many participants enjoyed the SSKAAT-R as it can help in the development of individualized interventions for persons with ID. This finding confirms that the tool is used for its intended purposes and is efficient in doing so. This is an important finding as it has been reported that the socio-sexual education of individuals with ID is most efficient when it has been individually created for a client (Dukes & McGuire, 2011). To elaborate, Dukes and McGuire (2011) stressed the necessity of individualized, one-on-one educational interventions where care is taken to match the educational approach to the learning style, skills, and abilities of the individual. Thus, clinicians may use the information gathered after administering the SSKAAT-R to build a set of tailored recommendations for an educational program (Thompson et al., 2016). This practice means that subsequent sexual health provisions are limited to topics contained within the assessment tool (Thompson et al., 2016).

In terms of reported weaknesses or limitations of the SSKAAT-R, many participants felt that some of the biggest weaknesses of the tool involved topics of sexuality that are lacking in terms of depth or missing altogether. For example, the tool had previously been critiqued for its largely heteronormative emphasis on sexual behaviour between men and women (Wilson et al., 2014) which was a concern brought forward and confirmed by a large portion of participants in the current study. Additionally, concern was raised by many that the SSKAAT-R does not address sexuality issues on the internet and knowledge of how to navigate online dating, sexting, and online pornography. Once again, findings of this second article align with previous research which had criticized the SSKAAT-R for not addressing internet safety and online sexuality. With that said, it has also previously been established that there is currently no sexual knowledge assessment tool for individuals with ID that contains questions related to online sexuality

(Thompson et al., 2016). Given this current oversight of a very important area of sexuality, an updated version of the SSKAAT-R would need to consider questions regarding sexuality and technology. The current study's findings also suggest that an updated version including an entire subtest of questions dedicated to online sex and safety is possibly needed.

Finally, overall findings on length of the tool did not support prior critique that the tool was too long. The majority of participants expressed that they believed the length of the tool to be "just right". However, as a new version would include added questions and possible subtests on sexuality and gender fluidity as well as internet or online safety, it would be prudent to consider that the tool may actually become longer in administration length. With that said, it remains possible for clinicians to pick and choose the subtests they want to administer in order to shorten the overall testing time.

4.3 Suggestions for Future Research

In order to expand upon the current findings described in this study, future research should focus on recruiting a larger number of participants, particularly in terms of the quantitative phase. Specifically, Wish et al. (1979) recruited 50 participants and Griffiths and Lunsky (1999) recruited 80 participants complete their survey. The current study had a total of 42 participants, which fell short of the intended goal. Fortunately, the project is ongoing, meaning that future participant recruitment is still possible and in development. It would be important and prudent to recruit a larger participant pool to obtain the perspective of more individuals using the tool in different areas of the world. Information from a larger sample of participants may change the overall picture of results and topics that were considered important in the current study. For instance, a participant in the current study who presently resides in Europe explained that it is often difficult for examinees to relate to some of the pictures in the

SSKAAT-R as they do not resemble their experience of the world in their own particular geographical area. This participant shared that the laminate card depicting an outdoor park does not look like the parks in their region. Indeed, these photos may resemble more often a park in North America. Taking this into consideration, it would be of interest and benefit to have more individuals from Europe and other parts of the world take part in the questionnaire in order to determine if the geographical location or cultural background of the examinee has an effect on how they choose to respond to the tool as a whole. Differences in opinions and attitudes may very well vary according the examinee's regional location (e.g. rural/urban differences).

Furthermore, differences may arise as a function of the examinee's political orientation or religious beliefs. Future research may want to consider gathering more specific information on the participant's location, political orientation, belief systems, and more. To elaborate, there are many factors that were unaccounted for in the current study which could be explored in the future. It is possible that some examinees may have difficulty with answering or scoring a point on certain questions of the SSKAAT-R which simply do not match up with what they know, such as the participant from Europe described. If certain questions are not answered "correctly" because of the individuals cultural background of reginal location, for example, they may score lower on their knowledge which would not reflect their true knowledge and/or abilities.

Although the majority of professionals who use the tool are most likely from America or North America, making it a priority to recruit participants in countries will lead to findings that may reflect broader and more diverse viewpoints. Without a doubt, a larger sample size will better reflect the opinions of the entire population of clinicians who have experience working with individuals with ID. As a result, a larger sample size may lead to increased validity and

reliability of the results and interpretations presented here. It will also lead to a better revised tool.

Given the nature of this ongoing project and with the end goal being to create a revised version of the SSKAAT-R, the current thesis is a valuable starting point for understanding the changes required to improve the tool for both clinicians and persons with ID. As a first step, the current thesis involved collecting the thoughts and opinions of professionals in the field who either use the SSKAAT-R and/or work with individuals with ID. However, in order to obtain a deeper and more precise understanding of current issues for individuals with ID, persons with ID, themselves, need to be queried. Therefore, future research should focus on conducting interviews with individuals diagnosed with an ID to collect information on what they think should be included. Also, future research should be geared toward insights into what sorts of issues persons with ID may be facing in their current lives with respect to sexuality. Ultimately, issues and topics of sexuality reported by individuals with ID can be compared to those that were identified as important by the professionals and clinicians in the current study. For instance, previous research has reported that professionals in the field who work with individuals with ID on issues of sexuality focus mostly on how to protect these individuals from abuse and exploitation (Stoffelon et al., 2013). Although a recognized and crucial component for socio-sexual education, individuals with ID may have a separate set of priorities such as building and maintaining relationships (Swango-Wilson, 2010). Thus, it would be of interest to confirm and explore the similarities and differences in priorities across these different groups. Accordingly, the content and structure of the SSKAAT-R may then be updated to better reflect the needs and interests of health care practitioners and clients, alike.

4.4 Clinical and Practical Implications

Socio-sexual assessment tools have been deemed a crucial component in developing individualized education programs for individuals with ID (Bell & Cameron, 2003; Galea et al., 2004; Garwood & McCabe, 2000). Specifically, professionals who work with persons with ID use assessment tools such as the SSKAAT-R to identify strengths or possible gaps in their knowledge. Consequently, choosing a socio-sexual assessment tool that is current and relevant is an important factor to consider when planning to appropriately educate persons with ID. Given that the overall goal of this manuscript-based thesis was to act as a first step in creating an updated version of the SSKAAT-R, the clinical implications are clear and meaningful.

To start, the SSKAAT-R was last updated eighteen years ago. The questions and topics in the tool reflect those that were regarded as important and valued for individuals with ID at that time. However, with the passing of almost two decades, there is a high probability that priorities in assessment and education have shifted over time. Indeed, it was noted by Griffiths and Lunsky (1999) that many subtle but important changes in priority were seen at that time, such as an increased emphasis on incest and other forms of inappropriate sexual contact, including rape. In 1999, this shift may have suggested growing awareness in the field that the increased risk of abuse among individuals with ID was not due to a vulnerability inherent to disability, but rather the result of an imbalance of power (Griffiths & Lunsky, 1999). Other changes observed in 1999 included significantly more attention to the topics of body parts, masturbation, and going steady when compared to results obtained in 1979. In 2020, however, examples of noted shifts included topics of birth control (services), homosexuality, and adult literature/movies. These were significantly more important than in 1999.

The use of an up-to-date assessment tool directly impacts the type of education provided to individuals with ID. In fact, researchers have demonstrated that sexual knowledge among individuals with ID is often lacking and that the possible consequences of such gaps in knowledge may well be detrimental for them. For example, individuals with ID who present with low levels of sexual knowledge may become more susceptible to abuse (Swango-Wilson, 2009; Tang & Lee, 1999; Watson et al., 2019), STIs (Aderemi et al., 2013; McGillivray, 1999), and unwanted pregnancies. Some authors have also suggested that limited knowledge of sexuality could be a factor in explaining the sexual offences of individuals with ID (Barron et al., 2002). Given the potential consequences of low levels of sexual knowledge in persons with ID, providing relevant and developmentally appropriate sexual education to these individuals is indispensable. Education is important for the protection of these individuals but also for fostering healthy sexual empowerment (Richards et al., 2012). On that note, individually-informed socio-sexual education would also help support individuals with ID to assert their sexual rights. As part of the four criteria that are necessary when working towards each individual being able to employ their rights, using a person-centered methodology is a crucial component in order to properly encourage informed decisions making about relationships and sexuality (Richards et al., 2012). This must be achieved to fully implement the sexual rights enshrined in the *United Nations Convention on the Rights of Persons with Disabilities* (United Nations, 2006).

Elsewhere, an important topic of discussion was the impression of many participants that the section on the SSKAAT-R concerning health-related questions may need to be removed from the tool altogether. According to many participants, the questions with respect to cancer, for instance, are too abstract and unhelpful for their clients. This finding provides important insight into how the tool is actually being used in the field and what is perhaps less helpful. Future

revisions of the tool may consider the removal of questions regarding cancer and cancer screening to accommodate more specific or relevant topics. Alternatively, researchers may choose to reword the questions to simplify the language for people with ID.

With that said, the current study provided insight regarding clinicians' use of the SSKAAT-R and how they adapted the measure for their own practice and purposes. For instance, although many interview participants indicated liking the tool because of the items addressing attitudes, it should be noted that a few participants revealed not using the attitude questions at all. Some clinicians were skeptical of using these kinds of questions to build intervention programs for individuals with ID because, for these clinicians, questions of this nature were based upon personal beliefs.

In addition, the versatility of the tool was also noted during the interview portion of the current study with some participants stating that they almost always used the SSKAAT-R from start to finish, while others pick and choose the subtests they prefer to administer. For example, one participant stated relying heavily on the Healthy Boundaries subtest to gain a thorough understanding of an individual's knowledge of sexual boundaries when dealing with persons with ID who have sexually offended. Relatedly, some participants stated sometimes skipping over questions regarding child rearing as it is often not an area of concern for the particular individuals they see. The SSKAT-R seems to be used as a function of the clinician's specific referral question for the individual being assessed. As such, being able to use the tool in a way that best meets the needs of a specific individual is an indispensable feature of the tool.

4.5 Overall Conclusion

This study has provided an initial understanding of what professionals in the field of disability and/or sexuality believe should be changed as well as updated to improve the

SSKAAT-R for individuals with ID. More broadly, current and relevant topics of assessment and education in sexuality were identified and compared to those considered important in earlier iterations. In addition to the exploration of these topics, specific strengths and limitations of the SSKAAT-R were highlighted. As a result, better assessment of the current needs and knowledge shortcomings of individuals with ID will lead to the development of better sexual education programs for this population that can empower this group and provide them a better quality of life.

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Appendix A

Laurentian University Research Ethics Board Approval

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X / Modifications to project / Time extension

Name of Principal Investigator and school/department	Katya Gessie, Psychology, Shelley Watson and Kelly Harding, co-supervisors
Title of Project	The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised: The Need for Updates in Assessment for Individuals with Intellectual Disabilities
REB file number	6020426
Date of original approval of project	October 16, 2019
Date of approval of project modifications or extension *(if applicable)*	
Final/Interim report due on: *(You may request an extension)*	October 16, 2020
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also, please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, *Laurentian University Research Ethics Board*

Appendix B

Google Forms Questionnaire

Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised (SSKAAT-R) Survey

The goals of the current study are to determine if the SSKAAT-R is representative of sexuality issues in the year 2020, such as the accessibility of sexuality content via the internet, advances in contraceptive methods, and updated terminology. Put another way, it is our intent to investigate the effectiveness of the SSKAAT-R in assessing current issues of sexuality for individuals with intellectual disabilities.

* Required

Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised (SSKAAT-R) Survey

Consent

Participant Consent Form

I agree to participate in the research project entitled "The Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised (SSKAAT-R): The Need for Updates in Assessment for Individuals with Intellectual Disabilities".

I understand that as part of a larger research project aimed to update the SSKAAT-R, the goals of the current study are to determine if the SSKAAT-R is representative of sexuality issues in the year 2020, such as the accessibility of sexuality content via the internet, advances in contraceptive methods, and updated terminology. Put another way, it is our intent to investigate the effectiveness of the SSKAAT-R in assessing current issues of sexuality for individuals with intellectual disabilities. This investigation of what needs to be updated or changed in the SSKAAT-R will improve the actual assessment of sexual knowledge. Consequently, we will be able to identify sexuality topics that are important for these individuals. If we are better able to understand the specific needs of this population, we can then modify sex education approaches accordingly. We can then provide education to people with intellectual disabilities in a more personalized manner.

I understand that I will be asked to complete a questionnaire on Google Forms. This questionnaire will take approximately 20 minutes to complete. During the questionnaire, I will be asked to share my thoughts and suggestions with respect to improving and updating the SSKAAT-R.

I understand that I do not have to participate in this study. I may stop participating at any time.

I understand that all information collected will be used for research purposes only. I understand that my anonymity will be protected. Any personal information collected during the study will stay private and confidential. Informed consent forms will be destroyed 10 years after completion of the study and only the primary researcher will have access to the data in the future for possible re-analysis. Demographic information will not be attached to questionnaire responses. If I want, I may receive a copy of the results a the end of the study (please check below).

If I have any questions regarding the purpose or nature of the study, I can call Shelley Watson, Ph.D. at 675 1151, extension 3334 or Katya Gessie, B.A. at 905-806-5767. If I have concerns regarding the ethics of the study, I may contact, Laurentian University Research Office at 705-675-1151 ext. 3213, 2436 or toll free at 1-800-461-4030 or email: ethics@laurentian.ca

1. Please check your preference for consent below. *

Mark only one oval.

- ( ) I have read the above consent information and voluntarily provide consent to participate in this survey.
- ( ) I do not wish to consent to participate in this survey.

Demographics

2. What is your age?

3. What is your gender?

4. What is your ethnicity?

5. What is your sexual orientation?

6. What are the first 3 letters of your postal code or zip code?

7. In what type of setting do you currently and primarily work?

Mark only one oval.

- ◯ Private practice
- ◯ University or academic setting
- ◯ School
- ◯ Hospital
- ◯ Outpatient mental health clinic
- ◯ Developmental disabilities community agency
- ◯ Government funded community clinical service
- ◯ Other: _____

8. How many years have you worked in the field of intellectual and developmental disabilities?

_____

Sexuality education

9. Rate your perceived importance of the following topics for assessment and sexual education individuals with intellectual and developmental disabilities. Please rate each topic only once.

Mark only one oval per row.

	definite exclusion	probable exclusion	uncertain	probable inclusion	definite inclusion
Body parts	◯	◯	◯	◯	◯
Masturbation	◯	◯	◯	◯	◯
Premarital sexual contact/limits	◯	◯	◯	◯	◯
Birth control - information; services	◯	◯	◯	◯	◯

Sexually transmitted infections - how to catch; symptoms; who to tell					
Intercourse					
Pregnancy					
Childbirth					
Homosexuality					
Incest and inappropriate sexual contact					
Extramarital contact/limits					
Inappropriate physical contact					
Marital procedures and responsibilities					
Marriage (General)					
Child rearing					
Alcohol					
Drugs - medication; marijuana; hard drugs					
Street pickups					
Rape					
Hitchhiking					
Adult movies and literature					
Cursing					
Nudity/exposure					

Voyeurism					
Suggestibility to dares					
Dating					
Going steady					
Engagement					

Testing Experience

10. What assessment measures have you used in your work when assessing sexual knowledge o attitudes or experiences of people with intellectual and developmental disabilities? Please check all that apply.

Check all that apply.

- [ ] The Sexual Knowledge, Experience, Feelings and Needs Scale (SexKen)
- [ ] The Human Relations and Sexuality Knowledge and Awareness Assessment
- [ ] The Assessment of Sexual Knowledge (ASK)
- [ ] The General Sexual Knowledge Questionnaire (GSKQ)
- [ ] The Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised (SSKAAT-R)

Other: [ ] _____

11. What led you to choose the assessments that you have used in the past? Please check all tha apply.

Check all that apply.

- [ ] Large research base for that test
- [ ] Instrument was readily available
- [ ] Cost of instrument
- [ ] Instrument fit the exact purpose of what you desired to test
- [ ] Previous training in that assessment
- [ ] Reputation of the assessment
- [ ] Ease of administration
- [ ] Wide range of factors were assessed
- [ ] Length of test

Other: [ ] ______________________

12. How familiar are you with the Socio-Sexual Knowledge and Attitudes Assessment Tool-Revised (SSKAAT-R)? *

Mark only one oval.

- ( ) Never heard of it
- ( ) Heard of it, but haven't used it
- ( ) Used it a few times
- ( ) Use it at least once a year
- ( ) Use it regularly (e.g., monthly)

Unfamiliar with SSKAAT-R

SSKAAT-R Introduction

http://youtube.com/watch?v=mV6fpPi5vA8

13. What is your reaction after watching the above Introduction to SSKAAT-R video?

Content and Format

14. Please specify in what context you use the SSKAAT-R.

15. How do you feel about the SSKAAT-R's length?

Mark only one oval.

- Should be much shorter
- Should be somewhat shorter
- The length is just right
- Should be somewhat longer
- Should be much longer

16. Are there any pictures in the SSKAAT-R that you believe to be confusing, irrelevant, or otherwise unhelpful? Please specify.

17. Are there any terms in the SSKAAT-R that you believe to be vague or ambiguous? Please specify.

18. Are there any questions in the SSKAAT-R that you believe to be vague or ambiguous or otherwise unhelpful? Please specify.

19. In your opinion, what are the strengths of the SSKAAT-R? Please specify.

20. In your opinion, what are the weaknesses of the SSKAAT-R? Please specify.

21. How would you describe the scoring and interpretation of the SSKAAT-R?

Mark only one oval.

- Very clear
- Somewhat clear
- Somewhat complicated
- Very complicated

22. Do you have any suggestions for improving the scoring of the SSKAAT-R?

23. Do you have any suggestions for improving the clarity of instruction in the SSKAAT-R's manu

SSKAAT-R Feedback- All

24. What is your overall impression of the SSKAAT-R?

Mark only one oval.

- Extremely unimpressed
- Unimpressed
- Neutral
- Impressed
- Very impressed

25. The SSKAAT-R is divided into 7 subtests, which are listed below. Please check which subtests should remain in an updated version of the SSKAAT-R.

Check all that apply.

- [ ] Anatomy
- [ ] Women's bodies (and knowledge of men's bodies)
- [ ] Men's bodies (and knowledge of women's bodies)
- [ ] Intimacy
- [ ] Pregnancy
- [ ] Birth control
- [ ] Healthy boundaries

26. Are there specific topics that you believe should be added to a revised version of the SSKAAT-R? Please specify.

27. Are there any specific topics that you believe should be removed from the SSKAAT-R? Please specify.

28. Do you have any other general suggestions for updating the SSKAAT-R?

Interview Participation

29. Would you be interested in taking part in an interview to further discuss your thoughts on the current SSKAAT-R and its future revision?

Mark only one oval.

- Yes
- No

Email address

30. Thank you for your interest in taking part in an interview! Please provide your email address below.

Register for Gift Card

31. Please enter your email to be registered for a chance to win a $30 Amazon gift card. Please limit your participation in this survey and registration for raffle to one time per person.

Appendix C

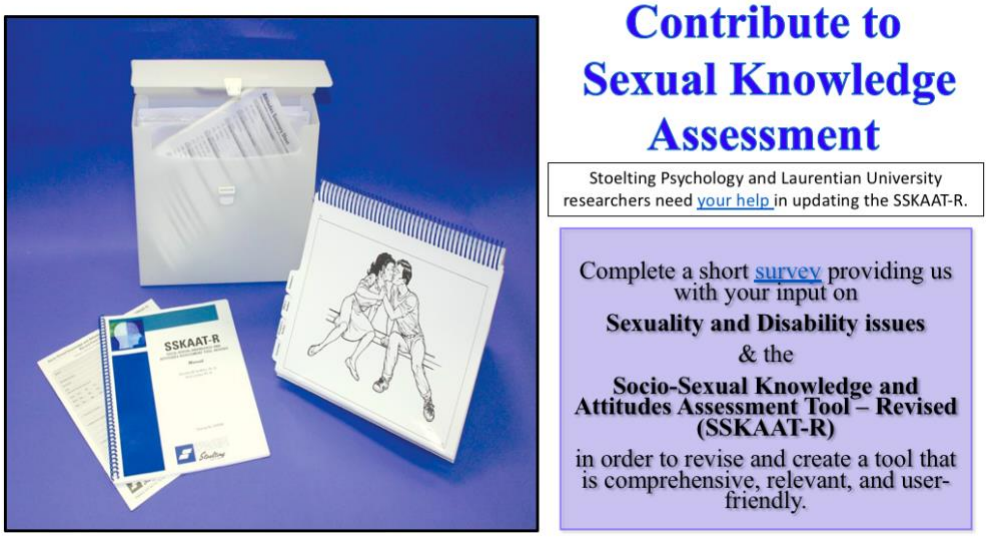
Semi-structured Interview Questions

1. In what context do you use the SSKAAT-R?
2. In your opinion, what are the strengths of the SSKAAT-R?
3. In your opinion, what are the weaknesses of the SSKAAT-R?
4. Are there specific topics that you believe should be added to a revised version of the SSKAAT-R?
    a. Prompt – any specific subtests
5. Are there any specific topics that you believe should be removed from the SSKAAT-R?
6. Are there any pictures in the SSKAAT-R that you believe to be confusing, irrelevant, or otherwise unhelpful?
    a. Prompt – show specific pictures that have been identified as problematic in the questionnaire portion of the study
7. Are there any questions in the SSKAAT-R that you believe to be vague or ambiguous or otherwise unhelpful?
    a. Prompt – show specific questions/terms that have been identified as ambiguous in questionnaire
8. Bring out SSKAAT. Do you have any suggestions for improving the size, format, or overall administration of the SSKAAT-R?
9. Do you have any other general suggestions for updating the SSKAAT-R?

Appendix D

Recruitment Notice

Electronic poster:



Recruitment email:

Hello, (name of professional/clinician).

Please permit me to introduce myself. My name is Katya Gessie and I am a graduate student in the Applied Psychology program at Laurentian University currently working on my master's research. The goal of my research is to update the Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised (SSKAAT-R) for individuals with intellectual disabilities. As a result, I am reaching out to you because you are a known professional in the field and I am hoping you would be willing to share your expertise with respect to what should be included in an assessment tool and if you are familiar with the SSKAAT-R, what you think should be revised. Your feedback will help create a new tool that is more user friendly as well as more representative of current issues of sexuality for these individuals.

If you would be interested in participating in this important study, the following link will lead you to a Google Forms survey. Your participation would be very valuable to this project and to future generations of practitioners and clients; however, the survey is short and respectful of your valuable time. If you choose to participate, you will have the opportunity to enter your email address in a raffle whose prize is an Amazon gift card.

I cannot stress how deeply appreciative and grateful I would be for your participation in this important research. Link: https://docs.google.com/forms/d/e/1FAIpQLSdVbZWQtOvCxjPAtcqEgsuAy2nywdxX9YBn2gchrwFP0rzOYw/viewform

Kind regards,
Katya Gessie
Graduate Student