JoDD

Journal on Developmental Disabilities
Volume 28 Number 3, 2023
On-Line First

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

L'évaluation socio sexuelle pour les individus ayant une déficience intellectuelle : Une comparaison de vingt et quarante ans

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Keywords

intellectual disability,
sexuality,
assessment,
socio-sexual education

Abstract

Very little is known about the socio-sexual knowledge and attitudes of adults with intellectual disabilities (ID) and tools to measure these constructs are limited. The purpose of the current study was to compare areas of importance in socio-sexual assessment for individuals with ID with those reported approximately twenty (Griffiths & Lunsky, 2000) and forty (Wish et al., 1980) 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 to be included in socio-sexual assessment 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 sexual orientation, birth control, and adult movies/literature appear to be of much greater importance in 2020. Ultimately, the comparison of topics of importance between years provides an up-to-date portrait of the necessary components of socio-sexual assessment for individuals with ID. The implications of this work highlight that an update in assessment can lead to more current understandings of the needs of this population as well as allow for more tailored approaches to sexual education.

Résumé

Très peu est connu au sujet des connaissances et attitudes socio sexuelles des adultes ayant une déficience intellectuelle (DI) et les outils pour mesurer ces construits sont limités. Le but de cette étude était de comparer les sujets d'importances dans l'évaluation socio sexuelle des individus ayant une DI avec ceux rapportés il y a environ 20 (Griffiths & Lunsky, 2000) et 40 (Wish et al., 1980) ans. Un total de 42 professionnels dans le domaine y compris des psychologues, des cliniciens et autres membres qui travaillent avec des individus ayant une DI on remplit un questionnaire dans lequel ils étaient demandés d'évaluer l'importance des sujets à inclure dans l'évaluation socio sexuelle des individus ayant une DI.

Les changements dans l'importance des sujets entre années sont explorés et expliqués en relation avec la littérature qui existe sur la sexualité en société et, spécifiquement, pour les individus ayant une DI. De manière générale, les résultats suggèrent que certains sujets restent importants à travers des années tels que le contact physique inapproprié, les rapports sexuels, les parties du corps et les infections transmises sexuellement. Autres changements entre années semblent refléter une meilleure appréciation et compréhension de la sexualité des individus ayant une DI. Par exemple, les sujets tels que l'orientation sexuelle, les méthodes de contraception et les films/littératures pour adultes semblent être beaucoup plus importants dans l'année 2020. En bref, la comparaison des sujets d'importances entre années fournit une mise à jour nécessaire sur l'évaluation socio sexuelle des individus ayant une DI. Les implications de ce travail soulignent qu'une mise à jour dans l'évaluation peut mener à une compréhension plus actuelle des besoins de cette population ainsi que permettre des approches plus adaptées quant à l'éducation sexuelle.

Mots-clés : Déficience intellectuelle, sexualité, évaluation, éducation socio sexuelle

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. (p.1)

At the time, non-consensual sterilization occurred because of the prevailing belief that individuals with ID would give birth to children who also have disabilities (Kempton & Kahn, 1991). 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, 1994). 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. There was also 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). 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 support and education (Gascoyne et al., 2016; Greenhill & Whitehead, 2011; McCann, 2010). Relatedly, 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). Some researchers suggest a general uneasiness among care workers to engage in conversations regarding sexuality with the individuals they support (Cuskelly & Bryde, 2004; Hamilton, 2009). The authors of an exploratory study conducted in Alberta, Canada that looked at the understanding and attitudes of direct care workers regarding the sexual practices of their clients with ID revealed a culture that mostly considers disability and sexuality as a topic to be avoided (Santinele Martino & Perreault-Laird, 2019). An important theme for social care workers in regards to the sexual relationships and needs of individuals with ID has been reported to revolve around the "influence of fear" or the fear of how others might perceive any actions on their part to support the sexual needs of their clients (Oloidi et al., 2022)

Undoubtedly, 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 for persons with ID, both in families and in the professional community (Tamas et al., 2019). When sexual education is catered to the specific needs of individuals with ID, it increases the ability of individuals with ID to make informed decisions about their sexual health and relationships (Dukes & McGuire, 2009). The potential consequences of limited sexual knowledge include a greater risk for abuse (Swango-Wilson, 2009) and a greater chance of contracting sexually transmitted infections (Aderemi & Pillay, 2013). Some authors have also found that limited sexual knowledge might account for the sexual offenses of some people with ID (Barron et al., 2002; Griffiths et al., 2013). Although 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).

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., 1980) 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 with limited 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. The topics included in the questionnaire were decided based on a literature review completed by the researchers (Wish et al., 1980). The inherent limitation in such an approach was that the participants could

only comment on the predetermined topics deemed relevant by the researchers. Participants were asked to rate each topic 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). The SSKAT was published in 1980 and 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 examinees thought that they knew about the subtest area.

In 2000, Griffiths and Lunsky distributed the Wish and colleagues (1980) 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 1980 items, some topics remained within the top ten priority list in 2000, 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. Respondents also provided topics they 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.

Overall, one of the most important changes to the 2000 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 sexually transmitted diseases (STDs); and healthy sexual boundaries.

Although the SSKAAT-R is one of the most comprehensive socio-sexual assessment measures, published criticism of the SSKAAT-R include the age of the assessment tool and its corresponding lack of content on new topics of importance (Thompson et al., 2016). The SSKAAT-R has also been criticized for its largely heteronormative emphasis on sexual behaviour between men and women (Wilson et al., 2014), as well as for the length of time that is required for administration (Ward et al., 2013). On the other hand, some of the greatest strengths of the SSKAAT-R have been documented as the breadth of the information it can assess (Watson, 2002) and its inclusion of pictures to maximize communication and comprehension (Wilson et al., 2014). The SSKAAT-R has also 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).

Given that the SSKAAT-R was last updated 23 years ago, and considering the prejudices against the sexual expression of individuals with ID that continue to exist today (e.g., Dinwoodie et al., 2020; Tamas et al., 2019), 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 (2000) 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 socio-sexual assessment for individuals with ID with those reported approximately twenty (Griffiths & Lunsky, 2000) and forty (Wish et al., 1980) years ago, respectively.

Materials and Methods

Procedure

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 2000 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 2000 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 socio-sexual assessment and education for individuals with ID. These topics included those used in both the 1980 and 2000 studies to capture changes in ratings over time and as such, the same language was used for these topics (e.g., homosexuality, street pickups, going steady). The following 25 topics were included for rating in the questionnaire: Body Parts, Masturbation, Premarital Sexual Contact/Limits, Birth Control, Sexually Transmitted Infections, Intercourse, Childbirth, Homosexuality, Incest and Inappropriate Sexual Contact, Extramarital Contact/Limits, Inappropriate Physical Contact, Marital Procedures and Responsibility, Childrearing, Alcohol, Drugs, Street Pickups, Hitchhiking, Adult Movies and Literature, Nudity/Exposure, Voyeurism, Suggestibility to Dares, Dating, Going Steady, and Engagement. Other questions in the questionnaire were open-ended to elicit additional feedback from participants, such as: *Are there specific topics that you believe should be added to a revised version of the SSKAAT-R?* 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.

Participants

In the current study, 42 participants responded to the questionnaire (see Table 1 for participant demographic characteristics). The majority of participants identified as being female (83%) and white (63%). 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	
Sex (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)
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: [a]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.

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. To analyze data regarding specific topics to be added to a revised measure, all responses that mentioned identical topics were tallied to calculate the associated percentages of participants mentioning a given topic.

Results

The 2020 results were compared to the 2000 and 1980 results using a two-sample z-score for difference between proportions (see Table 2 for the comparison of 1980 and 2020 and Table 3 for the comparison of 2000 and 2020). As was the case in the 2000 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 1980, 2000, and 2020. An alpha of .05 was considered to indicate a significant difference between years.

Changes in priority between 1980 and 2020

Comparing 1980 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 1980 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 1980 and 2020

Item	Definitely Important/ Total Response (%)		*Z* Score and Significance Levels
	2020	1980	
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

Changes in priority between 2000 and 2020

Looking at changes between 2000 and 2020, marital procedures/responsibilities and hitchhiking also remained 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 2000. 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 2000 and 2020

Item	**Definitely Important/ Total Response (%)**		***Z* Score and Significance Levels**
	2020	**2000**	
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 Information Services	36/42 (86%)	 69/80 (86.2%) 54/79 (76.5%)	 NS *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*=-2.41*p*=.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

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 2000 and 1980. 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, 2000, and 1980

	2020	**2000**	**1980**
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 2000 and number eight in 1980. 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 (see Table 5). One of the most frequently identified other topics 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.

Table 5

Participant Open-Ended Responses of Additional Topics

Suggested Topic	Relevant Sub-Topics	Frequency n (%)
Sexual and Gender Diversity	● LGBTQ2S+ issues ● Gender norms and challenging heteronormative identities ● Different and diverse expressions of sexual and gender identities ● Promoting less rigid views of sexual choices and moving beyond gender binaries of men and women ● Supporting transgender individuals ● Same sex intimacy	17 (40%)
Online Sexuality or Sex Over the Internet	● Texting ● Online dating ● Cell phone usage ● Internet safety of social media usage and online dating ● Having sex over the Internet	14 (33%)

Consent	● Ability to give and revoke consent ● Ability to recognize and respond appropriately to consent or lack thereof ● Understanding coercion ● Handling rejection ● Understanding healthy boundaries in diverse types of relationships ● Promoting knowledge of laws related to sexual interactions	10 (24%)
Healthy Relationships	● Awareness of violence and sexual violence, including harassment, assault, and rape ● Dating, courtship, and steps to initiate a romantic relationship ● Discussion of relationships beyond the heteronormative expectation of marriage ● Family planning ● Sexual responsibility ● Self advocacy and rights	10 (24%)
Pornography	● Laws around pornography (e.g., child pornography) ● Avoiding pathologizing pornography use ● Access to different forms of pornography (e.g., Internet pornography)	6 (14%)
Sexually Transmitted Infections	● Sexually transmitted infections ● Sexual hygiene	3 (7%)
Birth Control	● Responsible use of condoms, long acting forms of birth control, and contraceptive use	2 (5%)
Birth, Labour, and Parenting	● Issues pertaining to childbirth and labour ● Childcare to support parents with an ID	2 (5%)
Substance Use	● Impact of substances ● Alcohol and drug use during pregnancy	2 (5%)
Supports	● Awareness of supports ● Accessing legal and psychological services	2 (5%)

Notes: Frequency percentage does not equal 100% as participants could indicate more than one topic that should be added to a revised version of the SSKAAT-R. Six participants (14%) did not provide an answer to the open-ended question.

Furthermore, a substantial subset of participants (~40%) communicated the need for more emphasis on gender and sexual diversity. Issues related to individuals who identify as LGBTQIA2S+ and the request for less 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. Almost 25% of participants reported wanting more content on the topic of informed consent. The topic of consent is addressed 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." For a comprehensive summary of topics identified by participants on the open-ended question, see Table 5. 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.

Discussion

As part of a larger project aimed at updating the SSKAAT-R, the goal of the current study was to compare the areas of importance in socio-sexual assessment for individuals with ID with those reported approximately twenty (Griffiths & Lunsky, 2000) and forty (Wish et al., 1980) years ago. Data were collected by sharing a questionnaire with professionals in the field of disability and/or sexuality to obtain their thoughts on topics of sexuality.

2020 vs. 1980

The results comparing significant differences between the years 2020 and 1980 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 1980. 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 et al., 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 these 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 1980. 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 (Berger & Carlson, 2020). It has been suggested that the institution of marriage, in general, is becoming an outmoded institution that 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). However, from the perspective of individuals with ID, 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 was deemed significantly less important for individuals with ID now than it was in 1980. This finding is surprising given research elsewhere suggesting that women with ID are now accessing pregnancy-related services more than ever before (Brown et al., 2017; Homeyard et al., 2016). 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 live births 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 than 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.

2020 vs. 2000

When comparing the current results with those reported in 2000, adult movies/literature, sexual orientation (i.e., homosexuality), and birth control (services) are all areas of greater consequence. The rise in importance of sexual orientation 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, 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.

Researchers in the twenty-first century are, indeed, beginning to explore issues specific to people with ID who identify as LGBTQIA2S+. For example, researchers have suggested an increased diversity of gender identities and sexual orientations among autistic individuals compared to non-autistic peers (e.g., George & Stokes, 2018; Pecora et al., 2020). 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 (Duke, 2011; Meyer, 2003; Santinele Martino, 2022; Santinele Martino & Knitz, 2022). Hall (2010) reported that this prejudice and discrimination may create further marginalization and social exclusion and limit the opportunity for developing relationships. The theory of intersectionality suggests that one must consider the heterogeneity across different intersections of social positions in order to truly begin to understand an individual's unique experience (Crenshaw, 1989). The "double stigma" associated with disability and sexual orientation illustrates an example of the many types of prejudice an individual may face at the same time (Duke, 2011; Meyer, 2003). In the current study, the increased awareness of issues for individuals with ID who also identify with diverse sexual orientations was well demonstrated by the increased importance of this topic on the top ten priority list. Specifically, sexual orientation (i.e., homosexuality) 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 2000: 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 2000 may demonstrate its current inappropriateness or unsuitability in education and assessment.

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" (Schnepp, 1960, p. 240). 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 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, 2019). 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; Brennand & Santinele Martino, 2022). 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 et al. (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.

Limitations and Considerations

This study does have a few limitations that are important to note. First, not all of the topics covered in the 2000 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 2000 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 the COVID-19 pandemic. Third, given that this study aimed to replicate Griffiths and Lunsky's (2000) previous work, the statistical analysis chosen was solely descriptive in nature. However, the chosen analysis was able to support the goals of the study, providing insights into users' current thoughts and opinions on the tool, and allowed the comparison of responses over time.

Future work should include an in-depth look at attitudinal differences within participant groups. Specifically, attitudes and views may have differed depending on the participants' occupation or place of origin (i.e., Canada vs. United States). These potential differences should be explored within the context of the larger project and more broadly when talking about socio-sexual assessment and education, but it should be noted that the perceived needs of socio-sexual assessment and education for individual with ID may or may not differ from those of persons without ID. Future research should explore why some topics may be deemed important for individuals with disabilities and not for others.

Accompanying portions of the larger project will provide the researchers with an opportunity to elaborate on the findings presented here and to explore in more detail the results of the open-ended responses. Future publications will explore the results of qualitative interviews and focus groups to examine the specific strengths and limitations of the SSKAAT-R.

Conclusion

The results of the present study highlighted current topics of importance that should be considered for inclusion in socio-sexual assessment for individuals with ID. The results obtained in the present study were compared with those reported approximately 20 (Griffiths & Lunsky, 2000) and 40 (Wish et al., 1980) years ago to reveal changes that occurred between generations. As Griffiths and Lunsky (2000) 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. Indeed, it is encouraging to see topics such as birth control getting more recognition now, given that past 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 (e.g., Gougeon, 2009; Isler et al., 2009; McCarthy, 2009). Additionally, the topic of sexual orientation is deemed a more important point of discussion for individuals with ID today, which may speak to an overall acceptance that people with ID may also identify with diverse gender and sexual identities, just as others in the general population.

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, regarding 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 can simultaneously address the current lack of empirically based options for sex education among individuals with ID.

Key Messages

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, ensuring that individuals with intellectual disabilities have access to assessment and education to best meet their needs.

Messages clés

Les personnes ayant une déficience intellectuelle : Il est important que vous puissiez apprendre comment avoir de bonnes relations amoureuses et sexuelles avec d'autres personnes. Les personnes qui travaillent avec des individus ayant une déficience pensent que certains sujets sont très importants à apprendre.

Les professionnels : Les professionnels et ceux qui fournissent des services doivent être éduqués au sujet des implications d'une éducation sociosexuelle incomplète et sont encouragés à utiliser un outil tel que le SSKAAT-R afin d'adapter des programmes d'éducations plus spécialisés et individualisés.

Les décideurs politiques : Les décideurs politiques doivent également être éduqués au sujet des implications d'une éducation sociosexuelle incomplète. De plus, les décideurs politiques doivent aussi assurer que les individus ayant une déficience intellectuelle ont accès à une évaluation et éducation qui répond bien à leurs besoins.

References

Adams, G. L., Talon, R. J., & Alcorn, D. A. (1982). Attitudes toward the sexuality of mentally retarded and nonretarded persons. *Education and Training of the Mentally Retarded, 17*(4), 307–312. http://www.jstor.org/stable/23877299

Aderemi, T. J., & Pillay, B. J. (2013). Sexual abstinence and HIV knowledge in school-going adolescents with intellectual disabilities and non-disabled adolescents in Nigeria. *Journal of Child & Adolescent Mental Health, 25*(2), 161-174. https://doi.org/10.2989/17280583.2013.823867

Gerald J. Schnepp, S. M. (1960). Survey of Going Steady and Other Dating Practices. *The American Catholic Sociological Review*, *21*(3), 238–250. https://doi.org/10.2307/3708601

Baines, S., Emerson, E., Robertson, J., & Hatton, C. (2018). Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability. *BMC Public Health, 18*(1), 667-679. https://doi.org/10.1186/s12889-018-5572-9

Barron, P., Hassiotis, A., & Banes, J. (2002). Offenders with intellectual disability: the size of the problem and therapeutic outcomes. *Journal of Intellectual Disability Research, 46*(6), 454-463. https://doi.org/10.1046/j.1365-2788.2002.00432.x

Beber, E., & Biswas, A. B. (2009). Marriage and family life in people with developmental disability. *International Journal of Culture and Mental Health, 2*(2), 102-108. https://doi.org/10.1080/17447140903205317

Berger, L. M., & Carlson, M. J. (2020). Family policy and complex contemporary families: A decade in review and implications for the next decade of research and policy practice. *Journal of Marriage and Family, 82*(1), 478-507. https://doi.org/10.1111/jomf.12650

Blasingame, G. D., Boer, D. P., Guidry, L., Haaven, J., & Wilson, R. J. (2014). *Assessment, treatment, and supervision of individuals with intellectual disabilities and problematic sexual behaviors*. Association for the Treatment of Sexual Abusers, Beaverton (www. atsa. com/pdfs/ATSA_IDPSB_packet pdf).

Box, M., & Shawe, J. (2014). The experiences of adults with learning disabilities attending a sexuality and relationship group: "I want to get married and have kids". *Journal of Family Planning and Reproductive Health Care, 40*(2), 82-88. https://doi.org/10.1136/jfprhc-2012-100509

Bradshaw, C., Kahn, A. S., & Saville, B. K. (2010). To hook up or date: Which gender benefits? *Sex Roles, 62*(9-10), 661-669. https://doi.org/10.1007/s11199-010-9765-7

Braithwaite, S. R., Coulson, G., Keddington, K., & Fincham, F. D. (2015). The influence of pornography on sexual scripts and hooking up among emerging adults in college. *Archives of Sexual Behavior, 44*(1), 111-123. https://doi.org/10.1007/s10508-014-0351-x

Braun-Courville, D., Levin-Carmine, L., & Rojas, M. (2008). 2: The Impact of Sexually-Explicit Websites on Adolescent Sexual Attitudes and Behaviors. *Journal of Adolescent Health, 42*(2), 3-4. https://doi.org/10.1016/j.jadohealth.2007.11.015

Brennand, E. A., & Santinele Martino, A. (2022). Disability is associated with sexually transmitted infection: Severity and female sex are important risk factors. The *Canadian Journal of Human Sexuality, 31*(1), 91-102. https://doi.org/10.3138/cjhs.2021-0053

Brown, H. K., Cobigo, V., Lunsky, Y., & Vigod, S. N. (2017). Maternal and offspring outcomes in women with intellectual and developmental disabilities: a population-based cohort study. *BJOG: An International Journal of Obstetrics & Gynaecology, 124*(5), 757-765. https://doi.org/10.1111/1471-0528.14120

Brown, H. K., Lunsky, Y., Wilton, A. S., Cobigo, V., & Vigod, S. N. (2016). Pregnancy in women with intellectual and developmental disabilities. *Journal of Obstetrics and Gynaecology Canada, 38*(1), 9-16. https://doi.org/10.1016/j.jogc.2015.10.004

Brown, H. K., Ray, J. G., Liu, N., Lunsky, Y., & Vigod, S. N. (2018). Rapid repeat pregnancy among women with intellectual and developmental disabilities: a population-based cohort study. *CMAJ, 190*(32), E949-E956. https://doi.org/10.1503/cmaj.170932

Buck v. Bell, 274 U.S. 200 (1927). https://www.law.cornell.edu/supremecourt/text/274/200

Byers, E. S., Nichols, S., Voyer, S. D., & Reilly, G. (2013). Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship. *Autism, 17*(4), 418-433. https://doi.org/10.1177/1362361311431950

Coleman, E. M., & Murphy, W. D. (1980). A survey of sexual attitudes and sex education programs among facilities for the mentally retarded. *Applied Research in Mental Retardation, 1*(3-4), 269-276. https://doi.org/10.1016/0270-3092(80)90009-0

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum, 1*(8), 139-167.

Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample. Journal of *Intellectual and Developmental Disability, 29*(3), 255-264. https://doi.org/10.1080/13668250412331285136

Dekker, A., Safi, M., van der Zon-van Welzenis, E. I., Echteld, M. A., & Evenhuis, H. M. (2014). Sexuality and contraception in young people with mild intellectual disability; a qualitative study on the basis of 28 interviews. *Nederlands tijdschrift voor geneeskunde, 158*, A8010. https://europepmc.org/article/med/25387980

Di Giulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *Canadian Journal of Human Sexuality, 12*(1). 53-68. https://link.gale.com/apps/doc/A112167281/AONE?u=anon~2a9fcad2&sid=googleScholar&xid=2b19c73c

Dinwoodie, R., Greenhill, B., & Cookson, A. (2020). 'Them two things are what collide together': Understanding the sexual identity experiences of lesbian, gay, bisexual and trans people labelled with intellectual disability. *Journal of Applied Research in Intellectual Disabilities,33*(1), 3–16. https://doi.org/10.1111/jar.12252

Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research, 53(*8), 727-734. https://doi.org/10.1111/j.1365-2788.2009.01186.x

Duke, T. S. (2011). Lesbian, gay, bisexual, and transgender youth with disabilities: A meta-synthesis. *Journal of LGBT Youth, 8*(1), 1-52. https://doi.org/10.1080/19361653.2011.519181

Eze, I. R. (2014). Adolescents' attitude towards premarital sex. *Mediterranean Journal of Social Sciences, 5(*10), 491-499. https://doi.org/10.5901/mjss.2014.v5n10p491

Feng, J., Lazar, J., Kumin, L., & Ozok, A. (2008, October). Computer usage by young individuals with down syndrome: an exploratory study. In *Proceedings of the 10th international ACM SIGACCESS conference on Computers and accessibility* (pp. 35-42). https://doi.org/10.1145/1414471.1414480

Gascoyne, S., Hughes, E., McCann, E., & Quinn, C. (2016). The sexual health and relationship needs of people with severe mental illness. *Journal of Psychiatric and Mental Health Nursing, 23*(5), 338–343 https://doi.org/10.1111/jpm.12317

George, R., & Stokes, M. A. (2018). Gender identity and sexual orientation in autism spectrum disorder. *Autism, 22*(8), 970-982. https://doi.org/10.1177/1362361317714587

Gilmore, L., & Chambers, B. (2010). Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *Journal of Intellectual and Developmental Disability, 35*(1), 22-28. https://doi.org/10.3109/13668250903496344

Gomez, M. T. (2012). The S words: Sexuality, sensuality, sexual expression and people with intellectual disability. *Sexuality and Disability, 30*(2), 237-245. https://doi.org/10.1007/s11195-011-9250-4

Gordon, S. (1971). Missing in special education: Sex. *The Journal of Special Education, 5(*4), 351-354. https://doi.org/10.1177/002246697100500406

Gougeon, N. A. (2009). Sexuality education for students with intellectual disabilities, a critical pedagogical approach: outing the ignored curriculum. *Sex Education, 9*(3), 277-291. https://doi.org/10.1080/14681810903059094

Government of Canada. (2019, March 9). *Report on Sexually Transmitted Infections in Canada, 2017*. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/report-sexually-transmitted-infections-canada-2017.html

Greenhill, B., & Whitehead, R. (2011). Promoting service user inclusion in risk assessment and management: A pilot project developing a human rights-based approach. *British Journal of Learning Disabilities, 39*(4), 277-283. https://doi.org/10.1111/j.1468-3156.2010.00664.x

Griffiths, D., Hingsburger, D., Hoath, J., & Ioannou, S. (2013). 'Counterfeit deviance' revisited. *Journal of Applied Research in Intellectual Disabilities, 26*(5), 471-480. https://doi.org/10.1111/jar.12034

Griffiths, D., & Lunsky, Y. (2000). Changing attitudes towards the nature of socio-sexual assessment and education for persons with developmental disabilities: A twenty-year comparison. *Journal on Developmental Disabilities, 7*(1), 16-33.

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, *54*, 48-57.

Hamilton, C. A. (2009). 'Now I'd like to sleep with Rachael'–researching sexuality support in a service agency group home. *Disability & Society, 24*(3), 303-315. https://doi.org/10.1080/09687590902789461

Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives. *Journal of Intellectual Disability Research, 53*(11), 905-912. https://doi.org/10.1111/j.1365-2788.2009.01203.x

Heifetz, M., Lake, J., Weiss, J., Isaacs, B., & Connolly, J. (2020). Dating and romantic relationships of adolescents with intellectual and developmental disabilities. *Journal of Adolescence, 79*, 39-48. https://doi.org/10.1016/j.adolescence.2019.12.011

Hellemans, H., Roeyers, H., Leplae, W., Dewaele, T., & Deboutte, D. (2010). Sexual behavior in male adolescents and young adults with autism spectrum disorder and borderline/mild mental retardation. *Sexuality and Disability, 28*(2), 93-104. https://doi.org/10.1007/s11195-009-9145-9

Homeyard, C., Montgomery, E., Chinn, D., & Patelarou, E. (2016). Current evidence on antenatal care provision for women with intellectual disabilities: a systematic review. *Midwifery, 32*, 45-57. https://doi.org/10.1016/j.midw.2015.10.002

Isler, A., Tas, F., Beytut, D., & Conk, Z. (2009). Sexuality in adolescents with intellectual disabilities. *Sexuality and Disability, 27*(1), 27-34. https://doi.org/10.1007/s11195-009-9107-2

Johnson, P. R., & Davies, R. (1989). Sexual attitudes of members of staff. The British *Journal of Mental Subnormality, 35*(Part1-No 68), 17-21. https://doi.org/10.1179/bjms.1989.004

Katz, G., & Lazcano-Ponce, E. (2008). Sexuality in subjects with intellectual disability: an educational intervention proposal for parents and counselors in developing countries. *Salud Pública de México, 50*, s239-s254. https://doi.org/10.1590/s0036-36342008000800018

Kempton, W. (1975). *A teacher's guide to sex education for persons with learning disabilities*. Duxbury Resource Center.

Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability, 9*(2), 93-111. https://doi.org/10.1007/BF01101735

Kijak, R. J. (2011). A desire for love: considerations on sexuality and sexual education of people with intellectual disability in Poland. *Sexuality and Disability, 29*(1), 65-74. https://doi.org/10.1007/s11195-010-9184-2

Krebs, L. U. (2007). Sexual assessment: research and clinical. *Nursing Clinics of North America, 42*(4), 515-529. https://doi.org/10.1016/j.cnur.2007.07.004

Lumley, V. A., & Scotti, J. R. (2001). Supporting the sexuality of adults with mental retardation: Current status and future directions. *Journal of Positive Behavior Interventions, 3*(2), 109-119. https://doi.org/10.1177/109830070100300208

Lundberg, S., Pollak, R. A., & Stearns, J. (2016). Family inequality: Diverging patterns in marriage, cohabitation, and childbearing. *Journal of Economic Perspectives, 30(*2), 79-102. https://doi.org/10.1257/jep.30.2.79

Lunsky, Y., Frijters, J., Griffiths, D. M., Watson, S. L., & Williston, S. (2007). Sexual knowledge and attitudes of men with intellectual disability who sexually offend. *Journal of Intellectual and Developmental Disability, 32*(2), 74-81. https://doi.org/10.1080/13668250701408004

Mayo Clinic. (2021, March 17). *Sexually transmitted diseases* (STDs). https://www.mayoclinic.org/diseases-conditions/sexually-transmitted-diseases-stds/symptoms-causes/syc-20351240

McCann, E. (2010). Investigating mental health service user views regarding sexual and relationship issues. *Journal of Psychiatric and Mental Health Nursing, 17*(3), 251-259. https://doi.org/10.1111/j.1365-2850.2009.01509.x

McCarthy, M. (2009). Contraception and women with intellectual disabilities. Journal of *Applied Research in Intellectual Disabilities, 22*(4), 363-369. https://doi.org/10.1111/j.1468-3148.2008.00464.x

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin, 129*, 674–697. https://doi.org/10.1037/0033-2909.129.5.674

Mitchell, L.K., Doctor, R.M., & Butler, D.C. (1978). Attitudes of caretakers toward the sexual behavior of mentally retarded persons. *American Journal of Mental Deficiency, 83*(3), 289-96.

Neuman, R. (2020). Parents' perceptions regarding couple relationships of their adult children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 33*(2), 310-320. https://doi.org/10.1111/jar.12674

Niederbuhl, J. M., & Morris, C. D. (1993). Sexual knowledge and the capability of persons with dual diagnoses to consent to sexual contact. *Sexuality and Disability, 11*(4), 295-307. https://doi.org/10.1007/BF01102174

Nirje, B. (1994). The normalization principle and its human management implications. *SRV-VRS: The International Social Role Valorization Journal, 1*(2), 19-23.

Normand, C. L., & St-Louis, F. S. (2016). Risks and benefits of internet use by people with neurodevelopmental disorders. *Annual Review of Cybertherapy and Telemedicine, 14*, 219-222.

Oloidi, E. O., Northway, R., & Prince, J. (2022). 'People with intellectual disabilities living in the communities is bad enough let alone… having sex': Exploring societal influence on social care workers' attitudes, beliefs and behaviours towards support for personal and sexual relationship needs. *Journal of Applied Research in Intellectual Disabilities, 35*(4), 1037-1048. https://doi.org/10.1111/jar.12839

Pebdani, R. N. (2016). Attitudes of group home employees towards the sexuality of individuals with intellectual disabilities. *Sexuality and Disability, 34*(3), 329-339. https://doi.org/10.1007/s11195-016-9447-7

Pecora, L. A., Hancock, G. I., Hooley, M., Demmer, D. H., Attwood, T., Mesibov, G. B., & Stokes, M. A. (2020). Gender identity, sexual orientation and adverse sexual experiences in autistic females. *Molecular Autism, 11*(1), 1-16. https://doi.org/10.1186/s13229-020-00363-0

Perelli-Harris, B., Berrington, A., Gassen, N. S., Galezewska, P., & Holland, J. A. (2017). The rise in divorce and cohabitation: Is there a link?. *Population and Development Review, 43*(2), 303. https://doi.org/10.1111/padr.12063

Perelli-Harris, B., Kreyenfeld, M., Sigle-Rushton, W., Keizer, R., Lappegård, T., Jasilioniene, A., ... & Di Giulio, P. (2012). Changes in union status during the transition to parenthood in eleven European countries, 1970s to early 2000s. *Population Studies, 66*(2), 167-182. https://doi.org/10.1080/00324728.2012.673004

Pownall, J. D., Jahoda, A., Hastings, R., & Kerr, L. (2011). Sexual understanding and development of young people with intellectual disabilities: Mothers' perspectives of within-family context. *American Journal on Intellectual and Developmental Disabilities, 116*(3), 205-219. https://doi.org/10.1352/1944-7558-116.3.205

Pueschel, S. M., & Scola, P. S. (1988). Parent's perception of social and sexual functions in adolescents with Down's syndrome. *Journal of Intellectual Disability Research, 32*(3), 215-220. https://doi.org/10.1111/j.1365-2788.1988.tb01407.x

Rontos, K., Roumeliotou, M., Salvati, L., & Syrmali, M. E. (2017). Marriage or cohabitation? A survey of students' attitudes in Greece. *Demográfia English Edition, 60*(5), 5-31. https://doi.org/10.21543/DEE.2017.1

Rowe, W. S., & Savage, S. (1987). *Sexuality and the developmentally handicapped: A guidebook for health care professionals*. Edwin Mellen Pr.

Rushbrooke, E., Murray, C. D., & Townsend, S. (2014). What difficulties are experienced by caregivers in relation to the sexuality of people with intellectual disabilities? A qualitative meta-synthesis. *Research in Developmental Disabilities, 35*(4), 871-886. https://doi.org/10.1016/j.ridd.2014.01.012

Santinele Martino, A. (2022). 'I don't want to get in trouble': a study of how adults with intellectual disabilities convert and navigate intellectual disability sexual fields. *Culture, Health & Sexuality, 24*(9), 1230-1242 https://doi.org/10.1080/13691058.2021.1942552

Santinele Martino, A., & Kinitz, D. (2022). "It's just more complicated!": Experiences of adults with intellectual disabilities when navigating digital sexual fields. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace, 16*(2), 1-15. https://doi.org/10.5817/CP2022-2-6

Santinele Martino, A., & Perreault-Laird, J. (2019). " I don't know if I can talk about that": An Exploratory Study on the Experiences of Care Workers Regarding the Sexuality of People with Intellectual Disabilities. *Disability Studies Quarterly, 39*(3). https://doi.org/10.18061/dsq.v39i3.6383

Saxe, A., & Flanagan, T. (2016). Unprepared: An appeal for sex education training for support workers of adults with developmental disabilities. *Sexuality and Disability, 34*(4), 443-454. https://doi.org/10.1007/s11195-016-9449-5

Statistics Canada. (2019, March 10). *Canadian Internet Use Survey*. https://www150.statcan.gc.ca/n1/daily-quotidien/191029/dq191029a-eng.htm

Swango-Wilson, A. (2009). Perception of sex education for individuals with developmental and cognitive disability: A four cohort study. *Sexuality and Disability, 27*(4), 223-228. https://doi.org/10.1007/s11195-009-9140-1

Tamas, D., Jovanovic, N. B., Rajic, M., Ignjatovic, V. B., & Prkosovacki, B. P. (2019). Professionals, parents and the general public: attitudes towards the sexuality of persons with intellectual disability. *Sexuality and Disability, 37*(2), 245-258. https://doi.org/10.1007/s11195-018-09555-2

Thompson, V., Stancliffe, R., Broom, A., & Wilson, N. (2016). Clinicians' use of sexual knowledge assessment tools for people with intellectual disability. *Journal of Intellectual & Developmental Disability, 41*(3), 243–254. https://doi.org/10.3109/13668250.2016.1164303

Turk, V., & Brown, H. (1993). The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research, 6*(3), 193-216. https://doi.org/10.1111/j.1468-3148.1993.tb00053.x

Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013). A friendship and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities, 51*(1), 22-32. https://doi.org/10.1352/1934-9556-51.01.02

Watson, S. (2002). *Sex education for individuals who have a developmental disability: The need for assessment* (Unpublished master's thesis). Brock University. http://hdl.handle.net/10464/2054

Wilson, B. D., Cooper, K., Kastanis, A., & Nezhad, S. (2014). *Sexual and gender minority youth in foster care: Assessing disproportionality and disparities in Los Angele*. https://escholarship.org/uc/item/6mg3n153

Winges-Yanez, N. (2014). Why all the talk about sex? An autoethnography identifying the troubling discourse of sexuality and intellectual disability. *Sexuality and Disability, 32*(1), 107-116 http://dx.doi.org/10.1007/s11195-013-9331-7

Wish, J. R., McCombs, K. F., & Edmonson, B. (1980). *Socio-sexual knowledge and attitudes test (SSKAT) instruction manual*. Chicago, Stoelting Co.