Intellectual Disability and Sexual Health

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Abstract

Objective: To review literature on intellectual disabilities (ID) and sexuality with the following five emphases. The first aim is to describe attitudes and beliefs regarding sexuality and ID. The second aim is to describe the issues surrounding feminine health. The third aim is to describe the challenges of intimate relationships. The fourth and fifth aim is to explore the sexual rights of this population and the current interventions that are in place to address them.

Method: Pubmed (2000-2015), CINAHL (2000-2015), and PsycINFO (2000-2015) databases were searched for peer-reviewed articles using a systematic search strategy. Articles published in English and reporting on the aforementioned foci were considered.

Results: Out of Eighty-two articles that were included in this review, the majority of the studies on attitudes and beliefs showed that everyone in society, including college students, still have reservations about the sexuality of individuals with ID. Across all of the studies regarding male sexual behavior, it was discovered that the most common outlet for males to express sexual predispositions was through masturbation, which is often done in public places. Concisely, the most common types of inappropriate sexual conduct were the behaviors that occurred in public situations, involving self/others, and minors. Regarding the matter of intimate relationships, all individuals with ID desired to be part of intimate relationships. This would really make a positive impact on their mental health and well-being. Feminine health issues such as regular health screenings that include breast and cervical exams is lacking in this population. Finally, the majority of sexuality education/intervention programs were developed with no input from individuals with ID and most of them omitted topics about intimate relationships.

Conclusion: Attitudes and beliefs regarding sexuality and ID should be shifted. Parents, caregivers, and society should embrace the sexuality of individuals with ID. In the same way, regular health screenings should be conducted for both males and females of this population. Moreover, policies that are favorable should be established and current tailored sexual education programs should be more thorough and all inclusive.

Introduction

Statement of the Problem

The World Health Organization's (WHO) definition of sexual health states that sexual health is a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. In order for sexual health to be reached and maintained, the sexual rights of *all* persons must be respected, protected and fulfilled (WHO, 2002).

Generally, there seems to be a societal unawareness and denial of sexuality in people with ID. Complex topics such as sexual relationships in this population appear to produce stigmatized responses from the public (McConkey, 2013). People with ID are often prevented from getting married, having children, learning about sexuality, having sexual relationships and having access to sexual literature (Ailey, Marks, Crisp, and Hahn, 2003).

Communally, there are countless myths about the sexual health of people with ID, and there are significant barriers to sexual health provision for these individuals that includes, lack of favorable public policies, administrative constraints, family attitudes, and lack of staff training (Thompson, Stancliffe, Broom, and Wilson,2014). Nonetheless, individuals with ID has similar needs and desires about sexuality as individuals without ID (Mitchell, Doctor, and Butler, 1978) and it should be facilitated for them to experience and develop sexual relationships (Craft, 1987).

Assessing the issue of sexual health and ID, as well as the specific factors that hinder or promote sexual health in individuals with ID is difficult to attain utilizing standardized epidemiological approaches. The sexual issues facing this population remain largely undetected in the current US health surveillance systems. Hence, a systematic review of the published literature was undertaken to weigh these issues and the related factors that profoundly affect the sexual health of this population.

Methods

Inclusion criteria for this review include (a) adults with learning disabilities, low achievers, or mildly mentally retarded between the ages of 18-75, (b) unimpaired social cognition, (c) open mindedness, (d) cognitive flexibility/ IQ of 45-70, (e) uncompromised sexual development, and (g) individuals without a sexual conviction. Exclusion for this review include (a) adults with adults with learning disabilities, low achievers, or mildly mentally retarded below the age of 18 and over the age of 75, (b) impaired social cognition, (c) literal mindedness, (d) cognitive inflexibility/very low IQ below 45, (e) impaired sexual development, and (g) individuals with a sexual conviction. Included articles for this review include (a) longitudinal studies, and (b) intervention research studies. Excluded articles for this review include (a) case control studies, (b) cohort studies, (c) clinical trials, and (d) cross sectional studies. In addition, any duplicated articles from the three different sources, PubMed, CINAHL, and PsycINFO were also excluded.

Study publication date, location, population, and details related to and sexual health and ID are included herein. The review includes results of longitudinal studies, and intervention research studies conducted on individuals with ID at community-based organizations or home settings respectively.

Teaching their sons and daughters about how to manage autoerotic behaviors and overt signs of sexuality (Ballan, 2001).

Nevertheless, parents' difficulties with their children's sexuality need to be understood in the broader context of the children's social circumstances and family relationships(Pownall, Jahoda, and Hasting, 2011). It would a mistake to characterize the mothers who are anxious about this subject as overprotective when in fact, they are extremely conscious of their children's limited social opportunities in relation to their siblings and they desperately wish that their children could enjoy more fulfilling lives (Pownall et al., 2011).

In the same way, various studies regarding caretaker/caregiver attitudes toward sexuality and individuals with ID reports the varying perceptions as outlined successively. Cuskelly and Bryde (2004) reported that attitudes to sexual behavior in those with moderate intellectual disability were generally positive. There would appear to be a consensus that education about sexual matters is important, and there is little evidence that such education would be resisted (Cuskelly and Bryde, 2004). Caregivers of individuals with IDs approach their caregiving grounded on their own belief system. The beliefs system of each professional and parent normally have some impact on the education and services provided to the individual with ID (Brown and Pirtle, 2008).

Similarly, Evans, McGuire, Healy, and Carley (2009) highlighted that attitudes towards service-user sexuality and inconsistent approaches to the management of sexuality may hamper the advance of theoretical models of sexuality for those with an ID. The attitudes expressed by staff and caregivers, as opposed to family caregivers, more closely represented the ideological and theoretical developments in the area (Evans et al., 2009).

McConkey and Ryan (2001) stated that nearly 50% of staff identified more training and clear policy guidelines as the two main resources for increasing their confidence in dealing with issues of client sexuality. These results highlight the need for staff training and developing a collective approach to client sexuality (McConkey and Ryan, 2001).

Remarkably, there was a belief that women with ID should be offered less sexual freedom than women without disability. This implies that information about sex may at times be withheld by support workers and that negative reactions may be displayed when women with ID wish to engage in particular forms of sexual expression (Gilmore and Chambers, 2010).

Caregivers are often uncertain about the appropriateness of sexual behaviors within the ID population; although younger caregivers seem more accepting (Swango-Wilson, 2008). Sexual behaviors (public and private display of affection, safe sex, and risky sex) were rated as more appropriate for the caregiver and their peers than for the individual with ID (Swango-Wilson, 2008). Caregivers also felt that a person having an intellectual disability made it much more difficult to support them with sexual needs and decision-making. They felt a responsibility towards those they supported and identified a tension between reducing risk and increasing independence in sexuality and relationships in their clients (Swango-Wilson, 2008).

Meany-Tavares and Gavidia-Payne (2012) outlined that staff attitudes toward client sexuality were positive overall, and particularly for women with ID. In addition, while there is a clear need for further training in the area of sexuality, disability support workers, and older staff could benefit from targeted training (Meany-Tavares and Gavidia-Payne, 2012). In contrast, Young, Gore, and McCarthy (2012) indicates unfavorable attitudes towards sexuality in individuals with ID that correlate with traditional, restricted gender stereotypes. Theidentification of these themes highlights the importance of considering gender when supporting the sexuality of people with ID (Young et al., 2012).

Brown and Pirtle (2008) took their study a step further and made an effort to measure the perceptions of parents, caregivers, and professionals about the sexuality of individuals with ID that included sex education, birth control methods, and sexual participation (Brown and Pirtle, 2008). Their analysis produced four different types of belief systems that included (a) advocates, (b) supporters, (c) regulators, and (d) humanists.

More explicitly, the advocates were found to be strong supporters of human rights for individuals with ID including sexuality. The supporters were fervent supporters for sex education to be taught to individual with ID. Similarly, the regulators showed a strong preference toward educating individuals with ID regarding sex. However, in contrast, the regulators also supported extensive birth control measures. In conclusion, the humanists displayed the strongest support of human rights for individuals with ID as it relates to sex education, birth control, and sexual participation (Brown and Pirtle, 2008).

There is a need for improved support for caregivers to deal with the sexual needs of those with intellectual disabilities. Barriers for people with IDD should be acknowledged and attempts to reduce them at every level should be made (Rushbrooke, Murray, and Townsend, 2014). It is also suggested that the number of organizations that provides sexuality education to parents of individuals with ID be increased. This will help them receive professional education on sexual issues, reduces their anxieties, and diminishes the chance for distortion of information relating to sex in this population (Isler, Beytut, Tas, and Conk, 2009).

Generally, there is a continued need to provide staff and family caregivers with opportunities for dialogue and an ongoing need for training in the area of sexuality (Evans et al., 2009). It was concluded that special educators, nurses, social workers and physiotherapists show more approval (stronger acceptance and evaluation that is more positive) to most aspects of sexuality of people with intellectual disabilities (Meaney-Tavares and Gravidia-Paynes, 2012). Targeted training programs in sexuality can benefit direct care workers in general, and specifically older staff (Meaney-Tavares and Gravidia-Payne, 2012).

Masturbation. The most common incident that staff encountered in residential facilities where individuals with ID reside was public masturbation; although this was not the case in adult day programs (McConkey and Ryan, 2001). Masturbation is the main sexual expression and means of relief available to many people with ID (Kaeser and O'Neill, 1987). However, this is often seen as a problem since a number of difficulties has appeared as it result of this practice that include (a) act of masturbation in public places, (b) recurrent or prolonged masturbation, often without climax, and (c) performances that may cause injury(Kaeser and O'Neill, 1987).

There are very few reports documenting that masturbation techniques are being taught to individuals with ID. Nonetheless, there are insufficient examples that recommend how to teach individuals with ID the proper ways to masturbate safely and effectively (Eastgate, 2008). Education to encourage masturbation only in appropriate places should be provided as part of a broader program to encourage appropriate behavior in public places (Eastgate, 2008).

Masturbation is usually seen as morally wrong and individuals with ID who practice this behavior are normally chastised; however, masturbation is a normal and natural experience for women and men of all ages (Cuskelly and Bryde, 2014). Masturbation should be taught to adults with an ID as an acceptable form of sexual expression in sex education courses; it is also a good idea to ensure privacy at home for adults with ID who wish to masturbate (Cuskelly and Bryde, 2014).

In Yool, Langdon, and Garner (2003), staff was shown to have liberal attitudes with respect to the sexuality and masturbation; less liberal attitudes, with respect to sexual intercourse, homosexual relationships, and the involvement of adults with learning disabilities in decisions regarding their own sexuality (Yool et al., 2003).

Male sexual behavior. The most common types of inappropriate sexual conduct that were highlighted in Ward (2001) were the behaviors that occurred (a) in public situations, (b) involving others, and (c) involving minors (Ward, Trigler, and Pfeifer, 2001).Emphasis should be placed in the area of training for managing male sexual behaviors (Meaney-Tavares, 2012). Men with ID do express themselves sexuality, their desire to do so is underpinned by a normative biological urge, which sometimes develops into sexual practices that are affected by a range of individual and environmental factors that often ends up as sexual expression in unusual conducts (Wilson, Parmenter, Stancliffe, and Shuttleworth, 2011).

The term Conditionally Sexual summarized the responses of support workers that were interviewed regarding male sexual behaviors at their facilities. Their responses regarding this topic included (a) a need for sex education, (b) sporadic masturbation— depending upon cognitive function, (c) a need for males with ID to understand sexual relational and feelings—depending on their cognitive abilities (Wilson et al., 2011). The term was introduced to represent the delicate balance to reinforcing men's right sexuality, but this right is often limited due to the challenges that arise with more severe cognitive impairment and the socio-structural constraints of formal care settings (Wilson et al., 2011).

Numerous studies show an array of responses as it relates to male sexual behavior, as well as how certain disabilities may affect sexual behavior. These individuals are usually categorizes as learning disabled, low achievers, or mildly mentally retarded etc.For example, individuals with Autistic Disorder (AD) were found not to be significantly less sexually active than the individuals with Borderline/Mild Mental Retardation (MR); nonetheless, masturbation was common in both groups (Hellemans, Roeyers, Lepale, Dewade, and Deboutte, 2010). Whereas, individuals with MR had significantly more experience with relationships, although no difference was found in the presence of inappropriate or sexual orientation (Hellemans et al., 2010). Deviant sexual behaviors (stereotyped sexual interests; sensory fascinations with a sexual connotation; paraphilia) were present in the group with AD, but not in the group with MR; problems in individuals with AD were found to be more related to an obsessive quality of the sexual behavior (Hellemans et al., 2010).

Gresham, MacMillan, and Bocian (1996) explored the debate regarding the similarities and differences among groups of individuals labeled learning disabled, low achievers, or mildly mentally retarded to understand the perceived causes for the underachievement (Gresham, MacMillan, and Bocian, 1996).

They concluded that learning disability was typically defined on the basis of a severe discrepancy between ability and achievement. It represented unexpected under-achievement relative to one's ability level (ability-achievement discrepancy), and the presence of such a discrepancy validates the presence of a learning disability. Mild mental retardation, on the other hand, represented expected underachievement relative to one's ability (ability-achievement consistency), and underachievement was found to be caused by low aptitude. Finally, low achievement represented low academic functioning independent of ability and did not imply a particular causation (Gresham, MacMillan, and Bocian, 1996).

The Mental Capacity Act and the code of practice (Department of Health [DH], 2005) make it clear that people should not be treated as unable to make a decision about their own lives unless all feasible steps to help them to do so have been taken without success (Boyle, 2008). The Mental Capacity Act was implemented in 2007 to support individuals with limited decision-making ability. The Act appropriates for individuals who lacks capacity to make as many decisions as possible for them (Johnston and Liddle, 2007).

The Act lays down rules for substitute decision making. Someone taking decisions on behalf of the person lacking capacity must act in the best interests of the person concerned and choose the options least restrictive of his or her rights (Johnston and Liddle, 2007).

Future studies should focus on a person-centered approach and embracing healthy masculine sexuality; uncovering the layers that make-up one's sexual expression such as self-esteem, respect, sexual satisfaction, developmental aspects, and factors that support rewarding human relationships and developing the policy frameworks to support this within contemporary consent frameworks (Wilson et al., 2011).

Expectantly, implications of these finding will increase knowledge and skills related to sexuality and inappropriate sexual behavior and mental health resources needed to build community capacity to serve the ID population (Ward et al., 2001).

Intimate relationships

Meaningful relationships with others are often intangible for people with ID, but no less desired for their full inclusion and participation in society (Ward, Atkinson, Smith, and Windsor, 2013). Research has documented the value of interpersonal relationships and validated the strong connection between physical and mental health and the quality of an individual's social network including friendships, and intimate relationships (Kawachi, Subramanian, and Kim, 2008). However, very little attention has been paid to this essential human need in people with ID (Ward et al., 2013).

Studies have consistently documented that people with ID tend to have small social networks comprising primarily family members and staff, but the desire deeper and more meaningful relationships (Ward et al., 2013) and McMillan (2012) reported that many people ID were found to be lonely because they have limited opportunities to form meaningful relationships or experience a healthy sex life, which has produce a dehumanizing effect in this population (McMillan, 2012).

In attempting to measure the quality of life for persons with ID, interpersonal and intimate relations such as affiliations, affection, intimacy, close friendships, and connections are life experiences, which have been proven positively valued in this population (Schalock, Brown, Brown, Cummins, Felce, Matikka, and Parmenter, 2002).

Rushbrooke, Murray, and Townsend (2014) reported that all individuals with IDD valued being in intimate relationships that fulfill their needs and make a positive impact on their mental health and well-being. They also reported that relationships with friends could not meet the needs of physical expression and planning for the future that intimate relationships fulfilled. All participants from their study expressed the desire to share their sexuality, find opportunities for relationships, and receive support (Rushbrooke et al., 2014).

The study's participants reported they felt that their choices were being constrained by others, mainly caregivers. In contrast, caregivers should assist in providing opportunities for social contact, education about relationships, and consider alternative avenues to address the unmet needs including increasing social networks and social activities (Rushbrooke et al., 2014). Increasing the exposure of different types of relationships through education, increasing social networks, and friends is beneficial in expanding the parameters for relationship experiences (Rushbrooke et al., 2014).

Finally, Rushbrooke et al., (2014) proposed that changes in policy and training should include the sensitive management of the impact that caregivers have on relationships, emotional impact, and physical expression of relationships in IDD population (Rushbrooke et al., 2014). Listening and responding to people with IDD may empower the individuals and their caregivers in managing their sexual expression and intimate relationships (Rushbrooke et al., 2014).

Feminine Health

There is a critical need for health care providers to educate their patients with developmental disabilities about feminine health issues, including cervical and breast cancer screening; health care providers should work diligently to ensure that their patients with developmental disabilities receive cervical and breast cancer screening according to recommended clinical guidelines (Parish, Swaine, Luken, Rose, and Dababnah, 2012).

Cervical and breast cancer screenings. People with learning disabilities have unmet health needs and lower uptake of services and screenings(Gribben and Bell, 2010). There is evidence that women with learning disabilities do not get the same opportunity as other women to access cervical and breast screening (Gribben and Bell, 2010). The main issues identified were barriers to accessing services, which include attitudes and training of professionals, carers and services users, inadequate resources and invitation letters, and consent (Gribben and Bell, 2010).

Similarly, although women who experience premenstrual symptoms (PMS) are quite similar to those of women without ID, their menstrual management, interpretations, and attitudes to menses are influenced by their institutional life and by society (Chou, Lu, Wang, Lan, and Lin, 2008). There is a tendency to eliminate menstruation in women with ID, once any related problem arises. Nonetheless, menstrual elimination through medical interventions should be a last resort, as there is limited information about the long-term health effects. Practical strategies should include (a) communication, (b) preparing, (c) day-to-day symptom management, and (d) protective behaviors (Gomez, Carlson, and Van Dooren, 2012).

Appropriate allowance for families involved in feminine care of women with ID should include access to appropriate support as required. More tailored information and educational programs need to be provided to relevant professionals and carers (Chou andLu, 2012). Moreover, the interprofessional approach was found to be effective in delivering feminine care to people with ID. Interprofessional education has benefited, providers, students, lecturers and clients alike (Gibbs and Colclough, 2010).

Sexually transmitted diseases/infections. There is very little evidence pertaining to sexually transmitted diseases/infections (STD/STI) testing related to adults with ID. Similarly, very little is known about the rates of STD/STI in this population. This lack of references has to do with the fact that individuals with ID are less likely than other adults to be tested for HIV (Greenwood and Wilkinson, 2013). They were also found to have lower levels of knowledge regarding STD/STI and HIV prevention initiatives (Greenwood and Wilkinson, 2013). Other studies show an excess of risk to sexually transmitted infections among females in this population. Moreover, women with intellectual disabilities were found to be less likely to disclose sexual activities and are more likely to become victims of sexual abuse that may lead to an increase of STD/STI (Greenwood and Wilkinson, 2013).

Now in the matter of HIV/AIDS, this topic is fundamentally ignored in the population of people with ID. There seems to be a lack of recent epidemiological studies that conducted concerning to this population. In a nutshell, there is a scarcity of HIV prevalence data regarding people with ID (Brown & Jemmott 2002; Servais, 2006).

Estimations from international organizations such as UNAIDS indicate that people with disabilities have increased risk to HIV exposure (UNAIDS, 2009). The susceptibility of men with ID and HIV/AIDS may be due to sexual exploitation by men with and without ID (Sobsey, 1994; Sobsey & Doe, 1991) and the social marginalization of people with ID. HIV surveillance efforts among people with disabilities are limited in the United States, but individuals belonging to this population are sexually active; as a result, this matter should be investigated and prevention programs should be considered (Wells, Clark, and Sarno, 2014).

Sexual Rights

Many individuals with ID cannot intellectualize themselves as sexual beings. In fact, some of them regard sex as a dirty and inappropriate. Other people prohibiting them from engaging in sexual activity generally bring on this belief. The history of sexual suppression of people with intellectual disability is extensive and derives from primal fear of difference. The human rights imperative requires appropriate responses from services to support the sexual expression of people with ID (Gomez et al., 2012)

Since the declaration of the Individuals with Disabilities Education Act (IDEA) in 1975, the rights of individuals with ID have been an important topic of discussion in the United States. IDEAis a four part (A-D) piece of legislation that ensures students with a disability are provided with a Free Appropriate Public Education (FAPE) that is tailored to their individual needs. IDEA was previously known as the Education for All Handicapped Children Act (EHA) from 1970-1990.In 1990 Congress reauthorized EHA and changed the title to IDEA Public Law No. 94-142 (IDEA), which is comprised of four parts. IDEAis the first federal legislation to prohibit discrimination based on disability (CODE and ACT, 2000).

With the recent introduction of inclusion, normalization, and deinstitutionalization, many public schools have tried to prepare individuals with ID for the transition into mainstream communities (Yell, Rogers and Rogers, 1998). Individuals with ID have the same rights as individuals without disabilities. They have the right to work, to make friends, and to be an important part of our society (Yell, Rogers and Rogers, 1998).

By viewing the lives of people with disabilities as “intolerable” and the people themselves as “better off dead,” by infantilizing people with disabilities, or treating them like sexual monsters, a cycle of discrimination and abuse has propagated (Block, 2000). Women and men with cognitive disabilities in national and international self-advocacy movements such as Self Advocates Becoming Empowered are working together to achieve for inclusion into US communities, cultures, and equal protection under the law (Block, 2000). They are asserting their rights to care, counseling and educational services, and empowering people with cognitive disabilities to assert, protect and heal themselves (Block, 2000).

To help persons with mental retardation advocate for themselves and reduce the risk of being denied opportunities for appropriate socio-sexual development, providing sexuality, and relationship education to consumers that includes specific consideration of rights related to sexuality, marriage, childcare, and family living is essential(Oliver, Anthony, Leimkuhl, and Skillman, 2002).). Depending on the persistence of different sexual expression, standards for persons with and without mental disabilities, advocacy, and effective community integration strategies are highly needed to ensure appropriate resources and opportunities for persons with ID (Oliver et al., 2002).

These findings show that there is a need to educate people with ID about the laws relating to sexuality. It is important for them to understand the law and, given the high rates of sexual abuse perpetrated against people with ID, it is essential for them to benefit from the protection that these laws afford (O'Callaghan and Murphy, 2007).

Facilitators that would increase the sexual self-advocacy of individuals with ID are expanding access to information and sexual health services, removing systemic barriers, educating others, increasing access to counseling, and developing opportunities for sexual expression; reinforcement of the value of people with IDD as legitimate sources of information about their own experiences (Friedman, and Beckwith,2014)). Professionals and policy-makers need to consider strategies for reducing the stigmatization of people with intellectual disabilities, thereby enabling their inclusion in all aspects of community life (McConkey and Leavy, 2013).

Sterilization. Sterilization of men and women with ID remains a controversial issue in many countries throughout the world. This is primarily due to the fact these very men and women are usually unable to give or withhold consent to the procedure of sterilization (Stansfield, Holland, and Clare, 2007). The American Congress of Obstetricians and Gynecologists have defined women with ID (ACOG) as women "whose ability to participate in the informed consent process is, or might be, limited, and whose autonomy is, or might be, thereby impaired" (Insogna and Fiester, 2015).

The High Court of Australia ruled that all procedures involving the sterilization of children (other than to treat some malfunction or disease) should be referred to the Family Court of Australia in the early 1990's, but there has been much public debate about the sterilization of young women with ID (Carlson, Taylor, and Wilson, 2000). The issue of sterilization of men and women with ID seems to be a debated issue throughout many other countries. Implicit cultural assumptions about the sexuality and fertility of women with cognitive disabilities are embedded in United States history, and are still very noticeable today (Block, 2000). The prevalence of sterilization among women with ID in the US is three times higher than in the Belgian population and it is mainly correlated with factors related to the institution where these women live (Servais et al., 2004).

Medical technologies may have changed, but essential questions remain about intellectually disabled women's rights to participate in decisions about their own reproductive futures (Tilley, Walmsley, Earle, and Atkinson, 2012). The literature surveyed in this paper, and the voices presented, suggests that the restrictions placed upon women with ID to participate in and manage their own reproductive capacity have not gone away as institutionalization of this population have ceased (Tilley et al., 2012).

Referrals for sterilization are frequently for people with ID. In the case of the majority, it was thought as very unlikely that individuals with ID has ever had or will ever have sexual relationships (Stansfield et al., 2007). They also hypothesized that the request for sterilization is the consequence of a complex process reflecting concerns about the future and family issues. The relationship between lacking the capacity to consent to sterilization and the capacity to consent to sexual intercourse needs further exploration (Stansfield et al., 2007).

Although, many investigators views sterilization as a last resort, Insogna and Fiester (2015) contends that the antisterilization stance may be disservice to women with ID. They hold that sterilization should be considered as a legitimate option alongside other forms of contraception, and it does not necessarily need to be viewed as a last option (Insogna and Fiester, 2015). It should be used for the same kind of individualized purposes as used in women without ID. Providers should treat women with ID as unique individuals with different skills, different abilities, different strengths, and different deficits (Insogna and Fiester, 2015).

Laws that forbid sterilization of the mentally incompetent may be nearly as dehumanizing as the forced sterilization laws they replaced (Pham and Lerner, 2001). In considering the multifaceted medical and ethical issues that surrounds determining the patients' best interests, cautious individual case reviews with strict procedural safeguards should be considered (Pham and Lerner, 2001). Families should serve as the best substitute to express the choices of their incompetent adults with ID "Not allowing a caring family to express preferences regarding such life-altering experiences as pregnancy and childbirth may paradoxically silence the patient's voice" (Pham and Lerner, 2001).

Many studies have proven that individuals with severe intellectual disability are vulnerable and prone to exploitation. This is especially true when it comes to the matter of conducting research and performing certain medical procedures such as sterilization (Iacono and Murray, 2003).

The example of the Helsinki case is a prime example of ethical misconduct involving people with ID. The Declaration of Helsinki (World Medical Association, 2003) mandates that informed consent and proxy decision-making procedures be acquired before involving these individuals in research and other practices (Iacono and Murray, 2003).

As a result of detecting of this widespread exploitative practice, the UN Convention developed the guidelines for the Rights of Persons with Disabilities (Iacono and Carling-Jenkins, 2012). In the same way, the National Health and Medical Research Council (NHMRC) of 2007 issued the National Statement on Ethical Conduct in Research Involving Humans and Competence to Consent in Australia in 1999 in accordance with the NHMRC Act 1992 ((NHMR, 2007).

Iacono and Murray (2003) reports that the above specified examples serves as an illustration to highlight the role of legislation, various government bodies, and researchers in balancing principles of protection of vulnerable groups and rights to self-determination (Iacono and Murray, 2003).

Overall, it was recommended that information about sterilization and legal consent processes involving people with ID be publicized (perhaps repeatedly) through family, professional and disability networks (Carlson et al., 2000). Nonetheless, workers and parents of individuals with disabilities were found to be strongly against procreation and in favor of sterilization (Aunos and Feldma, 2002).

Sexual abuse. Male and females with ID were found to be at a higher risk of sexual abuse than other people in the community without ID (Valenti-Hein, 2002). This abuse may come from family members, support workers or roommates from the same household, day programs or work settings (Eastgate, 2008). Similar to individuals without disabilities, sexual abuse results in a range of emotional disorders such as anxiety and depression. Persons with ID tend to express emotional distress caused by sexual abuse by practicing self-injurious behavior, inappropriate sexual behavior or displaying obvious signs of reduced cognitive functioning (Mansell, Sobsey, and Moskal, 1998).

There is an overall lack of knowledge regarding behaviors that are sexually inappropriate; as a result there may be a lack of the ability to communicate or report any abuse that are experienced by members of the ID population (Tang and Lee, 1999). Normally, the numbers of cases that are actually reported are probably only a small proportion of the actual abuse cases that occurs in this population (O'Hara and Martin, 2001). Moreover, less cases of serious sexual abuse or assault are not dealt with by the court systems (O'Hara and Martin, 2001).

Nevertheless, individuals with limited communication skills can be taught to report abuse, with the help of educational materials such as dolls, sketches with appropriate illustrations, or mockups of appropriate and inappropriate touching (O'Hara and Martin, 2001). Parenthetically, only a person with appropriate skills and training should teach these educational and training efforts for sexual abuse. Once suitable educational methods are taught, individuals with severe intellectual disabilities may be able to learn the skills needed to report abuse and make decisions about how to reject unwelcomed sexual advances (O'Hara and Martin, 2001). As it relates to the matter of sexual abuse toward individuals with ID, the best protection that was shown is knowledge about sexual abuse. There is a huge need for educational programs to reduce the risk of sexual abuse in individuals with ID (Eastgate, 2008).

Current Interventions

Sexual Health Care

Many people with an ID do not receive the necessary attention regarding sexual health (Servais et al, 2006). Consequently, they are subject to obstacles from their environment that oppose interventions to promote sexual health (Dionne and Dupras, 2014). They are likely not to be offered the full range of choices for contraception and sexual health screening such as prostate or a Pap smear (Eastgate, 2008).

Moreover, the sexual hygiene of male with ID is lacking. The penile health needs of men and boys with ID are being compromised by a lack of guidance, training, knowledge, and limited gender-sensitive care (Wilson et al., 2011).Hygiene management, global gynecological care, and prevention of unplanned pregnancy, sexually transmitted diseases, and abuse have been frequently identified as areas in which the presence of intellectual disability dictates specific support needs(Servais et al., 2006). As a result, an individualized, person-centered, multidisciplinary approach that incorporates parents, caregivers, medical staff, educators, and the individual should be used to provide comprehensive sexual health care to persons with ID (Servais et al., 2006).

There are personal and environmental factors can influence the sexual health of individuals with ID either positively or negatively. The personal factors many include a physical and/or psychological restriction that affects the sexual life/health of people with ID (Dionne and Dupras, 2014). In the same way, the environmental factors include the personal microenvironment, the community eso-environment, the social exo-environment and the cultural macro-environment (Dionne and Dupras, 2014).

As outlined in the WHO definition, “sexual health requires a positive approach to sexuality and sexual relationships. In order for sexual health to be achieved and sustained, the sexual rights of all persons must be respected, protected, and fulfilled (WHO, 2002).It is imperative to establish the state of knowledge on the situation of people with an intellectual disability and their sexual health in order to determine the factors that help or hinder it(Dionne and Dupras, 2014). It is very important for the various interested parties and decision makers to cooperate and advocate for the prevention and the promotion of sexual health for people with ID (Dionne and Dupras, 2014).

McMillan (2012) also stated that regular education programs sexual health clinics for small groups of people who have learning disabilities allows the clinic to become a familiar environment for them. They can learn more about contraceptive options, sexually transmitted diseases/infections, cervical screening and testicular and breast self-examination (McMillan, 2012).

Education

Customarily, when parents are asked about sexual education for their children with ID, the most frequent answer that they provide was that they are unsure of how much their children should actually know about sexuality (Ballan, 2001). They fear that they may be setting themselves up for many problems ahead as their children might associate learning about sexuality with actual intentions to perform sexual activities (Ballan, 2001).

Specialists in the field have found that parents reported confused, anxious, and uncertain feelings toward the sexuality of their children, claiming both limited knowledge of sexuality and feelings of inadequacy in providing information on the subject to their sons or daughters (Ballan, 2001). Nonetheless, it has been proven that with professional guidance support and education, parents can gain a clear understanding of their sons or daughters sexuality that may equip them teach their children appropriately (Ballan, 2001).

In support of the positive effects of sex education for individuals with intellectual disabilities, several studies have indicated that sex education and discussions of sexuality successfully increase the knowledge of the individual with ID about sexual activity, contraception, reproduction, and personal hygiene (Ballan, 2001). Furthermore, the possibility that sex education effectively reduces the inappropriate sexual behavior of the individual with ID has been shown in many well-constructed studies (Whitehouse and McCabe, 1997). Observably, the need for sex education for individuals with ID seems apparent (Cuskelly and Bryde, 2004).

Based on the myriads of problems surrounding the subject of sexuality and ID, there is definitely a need for additional education on sexuality of both people with mental disabilities and their parents (Leutar and Mihoković, 2007). Individuals with ID are not receiving equitable information when compared to the education of the general population (Winges-Yanez, 2014).

In a recent Assessment of Sexual Knowledge (ASK) and Quick Knowledge Quiz (QKQ) that was administered to individuals with ID, poor overall knowledge of sexuality was revealed, particularly in the areas of sexually transmitted infections, sexual health, safer sex practices, legal issues and contraception in intellectually disabled individuals (Galea, Butler, Iacono, and Leighton, 2004).

On the same note, recent surveys of caregivers and service providers demonstrated a greater awareness of the fact that sexuality is a central part of personal identity, yet generally, restrictive or prohibitive attitudes dominate at both individual and organizational levels (Dukes and McGuire, 2009). Likewise, teachers that were included in another evaluation expressed negative attitudes and misconceptions about sexual education for individuals with ID. Theywere also found to be deficient of the skills needed to deliver sexuality education to learners in this population; this issue has to be addressed through proper training for teachers of individuals with ID (Aderemi, 2014). Inevitably, there is a need for greater education of caregivers, parents, teachers and a need for discussion of the complex issues regarding relationships and sexuality at a societal and policy levels (Dukes and McGuire, 2009).

During a study that was designed to evaluate the views of mothers having children with ID on sexual education for their children, Gurol (2014), mothers of males with ID expressed that sexual education was essential for their children. They agreed that institutions like rehabilitation centers should offer sexual education, but they do not (Gurol, 2014). These same mothers reported that they wanted sexual education to be provided for their children aimed at teaching young men of how to behave when they are stimulated. Parenthetically, also they reported that family planning and the actual act of sex was not required to be involved in this education; they believed that individuals with ID could not have a safe sex life without constantly being monitored or becoming at risk for engaging inappropriate sexual behaviors and abuse (Gurol, 2014).

In comparison to males, women were often found to display some sense of self-determinism in their sexual behavior; however, there was an undertone of negative perceptions of sex, which stems from self-imposed abstinence predicated by fear of intercourse, intimacy, or outcome (Bernert and Ogletree, 2013). Increasing self-efficacy perceptions and performance of safer sex practices to prevent negative sexual consequence is central to women’s sexuality education (Bernert and Ogletree, 2013). Sexuality education from a positive perspective that enhances their sexual self-determinism and encourages sexual health was recommended (Bernert and Ogletree, 2013).

General practitioners should be tasked with the responsibility of offering sexual health services such as information, contraception, and cervical and sexually transmissible infection screening, and to discourage inappropriate treatments such as sterilization for social rather than medical reasons, and androgen suppression (Eastgate, 2008). Moreover, since social workers as a whole, seems to be falling short in ensuring access to needed information regarding sexuality among people labeled with ID, they should educate themselves about effective methods that are currently available as well (Winges-Yanez, 2014).

In endeavoring to implement effective sexual education programs, utilizing critical teaching methods can help personnel develop a professional and adequate teaching model for sex education at schools/establishments for individuals with ID (Lofgren-Martenson, 2012). For instance, interviews may allow some insight into contextual issues, strategy, and aspects of sexual education that occur outside of the actual classroom; analysis of actual interactions can reveal patterns that occur between educators and learners when comprehension is questionable (Finlay, Rohleder, Taylor, and Culfear, 2015).

Addressing how sexual health education is delivered in practice and in detail provides valuable lessons about how such education can be improved (Finlay et al., 2015).

In addition, Computer-based interactive multimedia (CBIM) programs were found to be effective in increasing HIV/AIDS knowledge and skills among women with ID, who live both semi-independently and independently, in a single-session intervention (Wells et al., 2014). The CBIM program is not dependent on staff for instructional delivery; it is a highly efficient teaching tool and is an effective means to provide behavioral health content to the ID population (Wells et al., 2014).

Sexuality education tailored to the ID population can significantly improve the aptitude of individuals with ID to make sexually related decisions suitably. Their capacity to make sexuality-related decisions is not fixed; it can definitely be improved through individually tailored sex education (Dukes and McGuire, 2009).

Sexual health educators should dispel the current misconceptions about sexuality and disability, provide information on individual’s psychosexual development, and address the many strategies that can be utilized to promote appropriate behavior through comprehensive sexual education (Ballan, 2001).The provision of sex education training and promotion of positive attitudes towards appropriate sexual expression is critical to the realization of sexual autonomy for people with an ID (Healy, McGuire, Evans, and Carley, 2009).

Services and Education Programs

The majority of sexuality education programs currently in existence have been developed with no input from individuals with ID; failure to seek input from those whose lives are affected by any program tailored to them may result in limited understanding of self-perceived needs and thus, limited responsiveness to those needs are established(Swango-Wilson, 2010). “To develop a truly effective program it is necessary to have a free flow of communication between information provider and the individual seeking knowledge” (Swango-Wilson, 2010).

More specifically, some of the existing special education sexuality education curricula such as Family Life and Sexual Health (FLASH) ignore the importance of human relationships in the lives of individuals with IDcomponents (Schaafsma, Stoffelen, Kok, and Curfs, 2013). This current sex education programs and others like it are likely to be ineffective because the fact that they lack important components. All future sexual education program should be all encompassing, systematic, theory-based and evidence-based (Shaafsma et al., 2013).

Conclusion

In echoing many of the authors throughout this review, attitudes and beliefs regarding sexuality and ID should be shifted across all cultures. Individuals with IDD share the same hierarchy of needs as outlined in the Maslow’s Hierarchy of Needs; however, their priorities differ slightly. Individuals without ID are motivated to achieve certain needs and once a need is satisfied they seek to fulfill the next one. Nonetheless, in the ID population, it appears that one of the most important need, besides physiological, is love and belonging. Acceptance means everything to individuals belonging to this population, therefore, parents, caregivers, and society as a whole, should embrace the fact that individuals with ID have a desire for intimacy and provisions should made for them to achieve this life goal.

Males and females with ID should be taught about the various forms of relationships including intimate and sexual bonds. They need to know how to express sexual tendencies in private as well as in public locations properly. In the same way, health screenings that include breast, cervical, and prostate exams should be conducted regularly in this population. Moreover, policies that are more favorable should be established to protect this population from sexual abuse, allow them to get married, and have a say in their own reproductive issues.

Finally, tailored sexual education programs should be implemented wherever this population work and play; just as seen in traditional establishments where individuals without ID work and play. In addition, the current educational programs that aim to teach this population about sexuality should be more encompassing. The contents should include materials about the actual act of sex and the expressing of it, and intimate relationships. Further research should be conducted on the issue of sexuality and ID in order to create awareness about the inequalities and address the myriads of sexually related issues facing this population as discussed herein.

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Appendices

Figure 1 Search Strategy

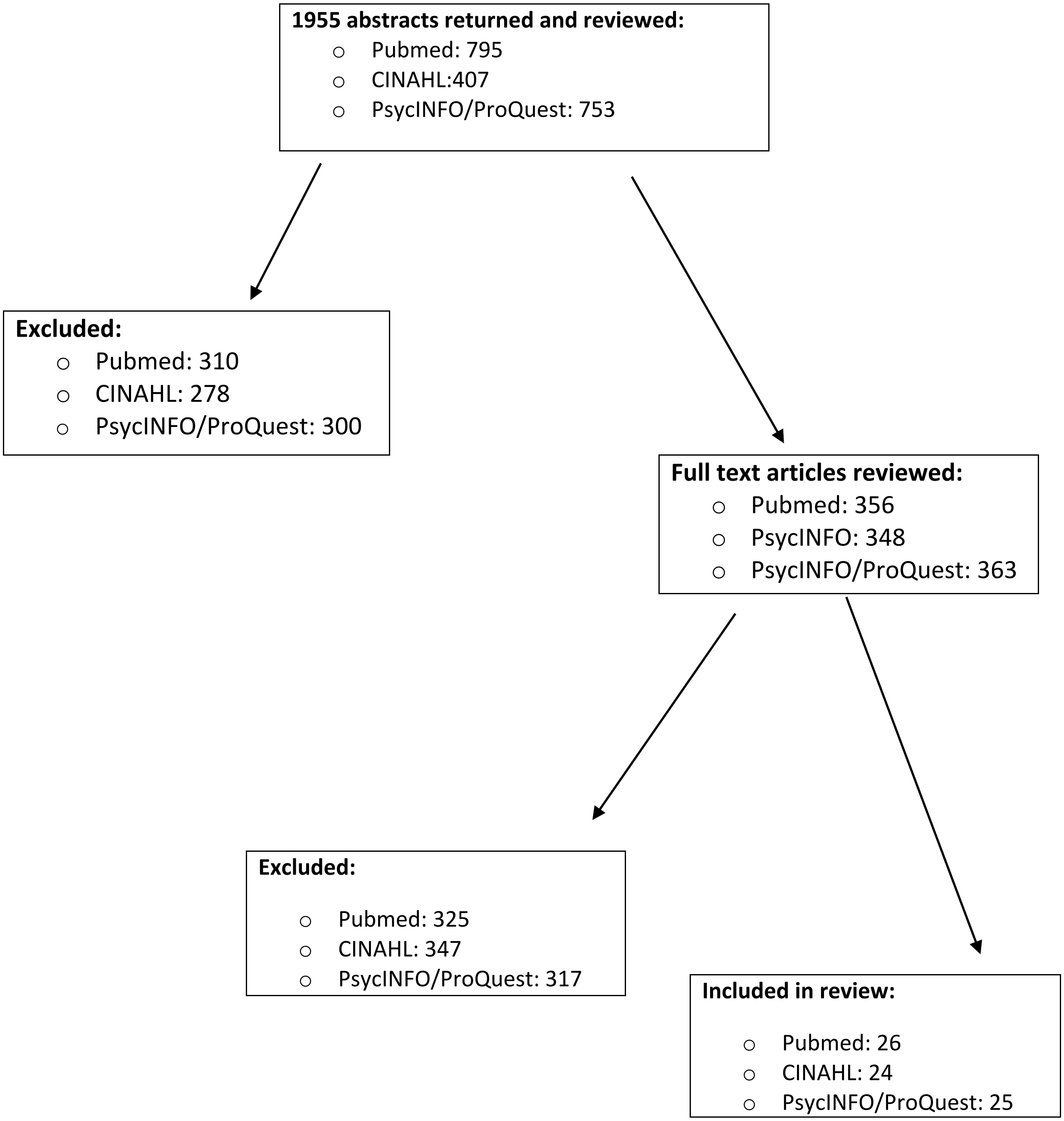

Table 1 Literature Search Terms

Database	Years Included	Search Terms *Used in conjunction with the words "Intellectual Disability"*
Pubmed	2000 through April 2015	1. Caretaker Attitudes 2. Education 3. Feminine Health 4. Male Sexual Health 5. Sexual Rights 6. Sterilization 7. Intimate Relationships
CINAHL	2000 through April 2015	1. Feminine Health 2. Male Sexual Health 3. Current Interventions 4. Sexual Health Care 5. Services and Support Programs 6. Masturbation 7. Sterilization 8. Education
PsychINFO/ProQuest	2000 through April 2015	1. Masturbation 2. Cervical and Breast Cancer Screenings 3. Sexually Transmitted Diseases/Infections 4. Sexual Assault/Abuse 5. Current Interventions 6. Sexual Health Care 7. Services and Support Programs 8. Sexual Rights

Definition of Terms

Autistic Disorder-(AD) or Autistic Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges.(National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention).

Developmental Disability-DD

Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. About one in six children in the U.S. have one or more developmental disabilities or other developmental delays. (National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention)

Intellectual Disability-ID

Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. (American Association on Intellectual and Developmental Disabilities)

Intelligence Quotient-IQ

Mental Retardation-MR

Mental retardation is a developmental disability that first appears in children under the age of 18. It is defined as an intellectual functioning level (as measured by standard tests for intelligence quotient) that is well below average and significant limitations in daily living skills (adaptive functioning); IQ score is usually below 70-75. There is an avoidance of the label "mentally retarded" as it is seen as ill-conducive to the betterment of knowledge in the field. (American Association on Mental Retardation).

Sexually Transmitted Diseases-STD

Any of various diseases or infections (as syphilis, gonorrhea, chlamydia, and genital herpes) that are usually transmitted by direct sexual contact and that include some (as hepatitis B and AIDS) that may be contracted by other than sexual means. (Florida Department of Health).

Sexually Transmitted Infections-STI

A sexually transmitted infection (STI) is an infection you can get by having sex. Some STIs (such as gonorrhea and chlamydia) infect your sexual and reproductive organs. Others (such as HIV, hepatitis B, and syphilis) cause general body infections. (Florida Department of Health).

Social Dominance Orientation-SDO

Social Dominance Orientation is one of the most powerful predictors of intergroup attitudes and behavior. (Society for Personality and Social Psychology).