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Reproductive Health Needs in Individuals with Intellectual and Developmental Disabilities

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TABLE OF CONTENTS:

1. Introduction.....	3
2. Literature Review.....	4
3. Methods.....	9
4. Discussion.....	9
5. Conclusions.....	14
6. References.....	16

INTRODUCTION:

Currently, 11.8 million individuals live with a cognitive impairment or are diagnosed with an intellectual or developmental disability (IDD) in the United States^{1,2,3} with approximately 820,000 women with IDD of reproductive age². Before the 1970s, this population had been largely institutionalized, facing stigmatization and unethical contraceptive methods including poor sexual and reproductive education, barriers to healthcare, and involuntary sterilization^{2,4,5}.

Living in state-funded institutions, private institutions, or with relatives or caregivers, this population is continuing to be integrated into communities with increasing societal recognition regarding their human rights, including sexual and reproductive health^{1,4}. With their integration into communities and education systems, adverse sexual and reproductive health outcomes are more evident than before¹. Women with IDD engage in sexual activity and have the ability to become pregnant, however due to barriers in healthcare access and sexual and reproductive education, this population is at an increased risk of adverse obstetric and gynecological outcomes including sexually transmitted infections (STI) and unplanned pregnancies.

For the purpose of this paper, intellectual and developmental disabilities will be defined as neurodevelopmental disorders beginning at birth or in childhood that are characterized by limitations in cognitive, communication, social domains, or adaptive skill^{4,6,7}. Intellectual disability will be defined with the International Quotient parameters and are as follows: Mild ID (IQ 50-70), moderate ID (IQ 35-49), severe ID (IQ 20-34), and profound (IQ 0-19)⁶. These intellectual and developmental disabilities in men and women of reproductive age, include but are not limited to cerebral palsy, spina bifida, and autism spectrum disorder (ASD).

The intent of this paper is to address the sexual and reproductive health disparities that exist in individuals with IDD. It will also attempt to outline recommendations for the treatment and management by healthcare providers around reproductive and sexual health in individuals with IDD.

LITERATURE REVIEW

Persons with intellectual and developmental disabilities (IDD) engage in sexual activity and are at an increased risk of unsafe sexual practices, placing them at an increased risk of STI, pregnancy complications and adverse pregnancy outcomes^{1,6,8}. This can be attributed to misconceptions regarding sexual and reproductive health, vulnerability, barriers to education and healthcare access, and increased rates of comorbidities and medical histories within this population.

Misconceptions By Providers And Caregivers

Persons with IDD engage in sexual activity at rates similar to their peers without IDD. This is despite a perception that this population is not at risk for STIs or unplanned pregnancy. In a study done by Baines et al, different demographics and socioeconomic factors including household composition, friendships, experiences of ever being threatened, and financial status were taken into consideration⁹. In their study pertaining to sexual activity, they found that 75% of 186 men with IDD reported engaging in sexual activity and of 115 women with IDD interviewed, 72% report ever being sexually active⁹. Compare this to 89% of 4150 men without IDD and 88% of 4287 women without IDD that report ever being sexually active⁹. A systematic review by Baines et al highlighted that up to 68% of parents report concerns of pregnancy in their children with IDD and would rather address sterilization, including tubal ligation and hysterectomies, resulting in the neglect of issues such as STI screening and prevention¹⁰. Until

recently, sexual healthcare in this population focused on pregnancy and sterility, rather than STI screening and management⁴.

Despite slightly comparable sexual activity levels this at-risk population is almost 50% less likely to receive adequate STI preventative care, screening, and education¹ when compared to their peers. The negative stigma and attitudes toward sexual activity exists in this population¹⁰ making them vulnerable to inadequate healthcare, and potential victims of sexual abuse and violence¹⁰.

Vulnerability

Individuals with IDD are likely to live with caregivers including family members or staff. This reliance on others for tasks of daily living provides them with minimal autonomy and privacy^{1,12}. In addition, the capacity for decision making varies between each individual and the ability or inability to make informed and consensual decisions may place this population in a vulnerable position regarding sexual abuse and violence⁴. In an Australian study, at least 25% of individuals with IDD were shown to be victims of sexual abuse and violence¹⁰. In a systematic review of 397 women with IDD living in a state institution, it was found that their counterparts living within the community were at a 3.5 times greater risk of becoming victims of abuse⁴. A lack of educated consent, poor social support, financial instability⁵, and being reliant on others for self-cares and daily living makes women with IDD vulnerable of becoming victims of abuse and contracting sexually transmitted infections⁴. A lack of understanding safe sexual practices, the transmission of STIs, and the potential lack of cognitive comprehension regarding the importance of conducting appropriate screening methods places this population at increased rates of STIs and unplanned pregnancies. These barriers in conjunction with limited resources and

access to reproductive healthcare and education contributes to poor reproductive health outcomes and the disparities that are seen between individuals with IDD and their peers⁴.

Barriers in Access to Reproductive Healthcare and Education

Individuals with IDD face various barriers regarding their sexual and reproductive health access and education. These individuals are more likely to live with their parents, be unemployed, have learning disabilities, and experience high levels of distress¹⁰. Because healthcare systems often rely on patients to advocate for their own healthcare needs and maintenance¹¹, sexual health risk assessments and supplemental information must be effectively communicated to the individual with IDD as well as their care team⁷.

A population-based study determined that 40.8% of sexually active women in state-funded facilities utilized contraception (sterilization, oral contraceptive pills, depo medroxyprogesterone acetate injections, and intrauterine devices)¹⁰. Condom use was reported as being used “often” by 2% of men with mild IDD that live in a group home and 28% reporting using condoms “sometimes”¹⁰. Knowledge gaps regarding obstetric and gynecological health in this population are substantial when compared to their peers^{1,9,11,12}, an example being 68% of individuals interviewed with IDD believed that contraceptive pills were effective methods of protection against STIs¹⁰. Assumptions exist due to barriers in education and comprehension.

Although women with IDD experience fertility at lower rate than their peers¹³, they have the ability to become pregnant despite the general population’s assumption that they are infertile. For women with IDD that do become pregnant, they are at an increased risk of adverse pregnancy outcomes⁸ and experience a greater prevalence of complications in pregnancy and labor and delivery. In the Canadian studies by Brown et al, they performed a retrospective cohort design study of all women within Ontario that had given birth between 2002 and 2012. Utilizing

International Classification of Diseases, ninth revision (ICD-9) codes and social service reports, they were able to identify 3,932 deliveries to women with IDD. Their results indicated that women with IDD are at a higher risk pregnancy complications including venous thromboembolism (VTE), preeclampsia, poly/oligohydramnios, fetal distress, premature rupture of membranes, preterm birth, small for gestational age (as defined as less than the tenth percentile), and low APGAR scores when compared to women of the same age, ethnicity, and comparable economic status^{7,13}. They are also at an increased risk for cesarean sections, congenital infections⁶, longer hospital stays, and are more likely to have to return to the hospital postpartum⁴. Furthermore, women with IDD have a fetal death rate of 2.8% compared to their peers that had a fetal death rate of 0.4%. In addition, more infants being more likely to be stillborn, die within the first week of their life, or preterm¹¹.

These adverse pregnancy outcomes can be attributed to chromosomal and hormonal differences¹⁰ as well as barriers to preventative healthcare and education. This population is less likely to recognize signs of pregnancy, seeking prenatal care later and less often than their peers^{11,12}. Varying cognitive abilities can also impact their comprehension of warning signs including abnormal vaginal bleeding or infection during and after pregnancy; the lack of understanding results in fewer healthcare visits¹² and an increase in adverse health outcomes. Additionally, limited resources including transportation and healthcare access reduces the frequency and monitoring of pregnancy and postnatal healthcare visits¹². This is a result of their lack of understanding appropriate healthcare and follow up, as well as the monitoring of warning signs.

Individuals with IDD face a variety of barriers when it comes to their sexual and reproductive health. These barriers in conjunction with their increased rates of comorbidities and

complex health histories makes healthcare prevention, intervention, and education difficult. Sexual and reproductive health is multifactorial and must be understood and supported by healthcare providers.

Comorbidities Relevant to Reproductive Health

Increased rates of comorbidities including obesity, seizures, and thyroid dysfunction are prevalent in those with IDD making the treatment and healthcare management difficult⁴. Immunological impairment is often present in individuals with IDD, placing them at an increased risk of infections related to STIs and postnatal cares⁴. This population experiences higher rates of emergency department (ED) visits and hospital admissions when compared to a cohort of similar age⁴. Providers must understand the physiological differences and comorbidities in order to help eliminate communication errors and increase effective non-pharmacological and pharmacological treatment. This population's lack of education and understanding may result in difficulty distinguishing appropriate sexual health practices and preventative health measures, leading to adverse sexual health outcomes.

Often, self-monitoring of signs and symptoms related to sexual and reproductive health are not be communicated or recognized in women with IDD. The integration of standardized sexual health screening and education guidelines for females with IDD has been implemented into some electronic medical record (EMR) systems in Canada. This has assisted in routine and standardized sexual and reproductive health screening for women with IDD¹¹. This population is diverse in their abilities and needs, thus additional considerations and interventions as well as additional time is necessary for the management of their sexual and reproductive health and education¹.

METHODS

A literature review utilizing PubMed and Google Scholar were used for the purpose of this paper. Key words included, “Sexual health in the special needs population”, “pregnancy in women with intellectual and developmental disabilities”, “pregnancy outcomes in special needs women”, “sexually transmitted infections in individuals with intellectual and developmental disabilities” “sexual abuse in the special needs community” and “intellectual and developmental disabilities”. Inclusion criteria included articles that were peer reviewed. The studies were no older than ten years old (2009) except for two studies; these two studies were deemed appropriate due to the limited research in the field of sexual and reproductive health in individuals with IDD and are some of the most referenced studies in the field. Excluded articles were those that were not written in or translated to English. Age parameters were not implemented for the purpose of this paper due to sexual and reproductive health concerns beginning prior to 18 years old. Full articles that were not accessible through the search engines PubMed or Google Scholar, were requested through Augsburg University’s Lindell Library’s interlibrary loan.

DISCUSSION

This paper sought to investigate the sexual and reproductive health disparities in individuals with IDD. With these findings, recommendations for healthcare providers and caregivers of individuals with IDD can be given in an effort to reduce the poor sexual and reproductive health outcomes that exist as a result of misconceptions, vulnerability, comorbidities, and barriers to education and healthcare.

The topic of sexual and reproductive health is stigmatized within the community and by the parents and caregivers of individuals with IDD. Parents often report concern about their

children with IDD regarding abuse and vulnerability and possess feelings of awkwardness and hesitation when addressing sexuality and sexual health¹. Despite feelings of uncomfortableness, these concepts should be introduced prior to the onset of puberty and continued to be addressed throughout development and adulthood. The introduction of this sensitive topic at a younger age will bring awareness to the individual's sexual and reproductive health allowing them to advocate for themselves and providing an understanding of autonomy and self-ownership of their body. The normalization of this topic and the understanding of sexual and reproductive rights and boundaries will help to reduce the vulnerability in individuals with IDD. Sexual and reproductive health should be a normal part of the individual's health maintenance and be a topic of conversation that can be shared between healthcare providers, the patient, and their care team. Furthermore, having early conversations regarding this sensitive topic will help reduce the misconceptions that exist within this population as they pertain to sexual and reproductive health.

Healthcare providers have the potential to assist in the normalization of the topic regarding safe sexual and reproductive health. They can be a resource for parents, caregivers, and most importantly the patient with an IDD. They can also serve as advocates for the rights of sexual and reproductive autonomy that individuals with IDD possess. During healthcare visits, providers have an opportunity to be a catalyst in initiating uncomfortable and often stigmatized conversations between parents, caregivers, and the patient with IDD regarding the topic of sexual health.

The stigmatization regarding sexual and reproductive health needs to be addressed in a manner that is sensitive and respectful for all parties involved. With the utilization of longer office visits, healthcare providers can address and normalize the sensitive topic of screenings and conversations relevant to individuals with IDD. These constructive conversations and office

visits must be centered around the individual with IDD and their health needs in an effort to reinforce safe sexual practices and sexuality¹. However, conversations with their caregivers and parents must be integrated into routine visits to ensure the patient is supported by all members of their care team while addressing the barriers that the individual may be faced with.

Oftentimes, barriers to sexual education, healthcare, and communication can lead to inappropriate sexual behaviors and exploration¹ as well as unplanned pregnancies¹. The barriers that exist in correlation with sexual and reproductive health must be navigated despite the negative stigma associated with this topic. Addressing barriers to preventative healthcare and education is essential in order for modifiable risk factors to be addressed in hopes of decreasing the risk of STI transmission and poor pregnancy outcomes^{11,12}. Due to this population's cognitive limitations⁶, additional time and resources, including collaboration with educators and therapists, may be necessary in order to properly educate and screen the individual for sexual and reproductive health concerns. This collaboration should be in the best interest of the individual with IDD, keeping them at the forefront of their treatment plan in an attempt to reduce their adverse health outcomes.

It is essential that preventative health measures and routine assessments including pap-smears, STI testing, and feelings of safety be addressed regarding the stigmatized topic of sexual and reproductive health in individuals with IDD. The earlier introduction of sexual and reproductive health will allow for the normalization of STI testing and screening. Utilizing pictures and adaptive communication systems will help accurately convey the purpose of screening in an individualized manner. These picture and communication systems address sexuality for all abilities and are offered by different education and wellness companies including Mad Hatter Wellness of Minnesota. Augmented communication systems with the

assistance of occupational and speech therapists will assist in the ethical obtaining of informed consent when addressing the topic of sexual and reproductive health screenings. Healthcare providers must recognize and be equipped for the various disparities that exist within this population. These individuals typically possess complex medical histories and experience higher rates of chronic disease and comorbidities¹ making their treatment and management more complicated when compared to their peers^{1,6}.

Healthcare providers and healthcare systems have the potential to address barriers that exists within the healthcare community. Limited access to healthcare within this population, and the complexities of the patient's health history can often lead to the topic of sexual and reproductive health being neglected. The implementation of standardized screening questions and recommendations can ensure that appropriate screenings and topics are addressed during office visits. The implementation of standardized guidelines into electronic medical records (EMRs) and health systems will allow for preventative health measures to be taken regarding STI and reproductive health disorders within individuals with IDD. A set of standardized questions and guidelines that auto-populate in EMR systems will enable healthcare providers to appropriately diagnose and assist in making informed decisions in the best interest of their patients.

Currently, the United States does not possess standardized guidelines regarding sexual health screening and education for individuals with intellectual and developmental disabilities¹¹. The implementation of standardized screening and education will help to reduce the stigma associated with sexual and reproductive health in this population. Utilizing Canadian guidelines as parameters for the initial implementation of standardization sexual and reproductive health

assessments in individuals with IDD will assist in decreasing the risk and rates of reproductive health disparities including STIs and poor pregnancy outcomes.

In 2018 the Canadian Family Physicians updated their healthcare guidelines, utilizing empirical knowledge (research derived from randomized control trials—RCTS, and observational studies; ecosystemic knowledge (population data from prevalence of healthcare systems); expert knowledge (healthcare practitioners and professionals) and experiential knowledge (patients and caregiver perspectives) to implement prevalent health issues in individuals with IDD and to optimize the standard of care¹¹. These updated guidelines have implemented Guideline 19: Women’s gynecological and reproductive health. Modules and strategies have been incorporated into their national EMRs to help outline implementation tools for collaboration and best practices with the individual and their caregivers¹¹. These guidelines can encourage health systems in the United States and around the world to advocate for optimized sexual and reproductive healthcare in all populations, including individuals with IDD.

Further research regarding sexual and reproductive health education and management will be necessary. The majority of studies regarding pregnancy and pregnancy outcomes in women with intellectual and developmental disabilities state that additional research is required. Limitations of the studies can be attributed mis-classification of intellectual and developmental disability or lack of a diagnosis with few women actually assigned an ICD-9 code¹¹. Variability in studies and small sample sizes⁹, the inability to control the social environment of the individuals with IDD as well as variations in their disabilities, contributes to reported inaccuracies in the research. Additionally, cultural definitions and stigmatization of individuals with IDD can contribute to misclassification⁴. For most of the reported studies, information was often obtained from caregivers of individuals with IDD or with a caregiver present¹⁰.

This population is a heterogeneous group that requires individualized time and attention in order to appropriately address preventative health measures. Preventable health conditions including STIs and adverse pregnancy outcomes can be reduced with the utilization of additional office visit time as well as standardized clinical tools. This will allow for patients of various cognitive, communicative, physical, and adaptive functioning to obtain adequate healthcare and education in hopes of reducing adverse sexual and reproductive health outcomes.

CONCLUSIONS:

Sexual and reproductive health in individuals with intellectual and developmental disabilities is a very complex and multifactorial topic. Although additional research and systematic studies are warranted, the current data regarding adverse sexual and reproductive healthcare and education indicates that a disparity in health outcomes exists when compared to their peers.

It is evident that individuals with IDD are at a decreased rate of sexual and reproductive education and health screening, placing them at increased risks of unsafe sexual practices. Their dependence on others for the management of daily affairs places this population in a vulnerable position susceptible to physical and sexual abuse. Barriers to appropriate health education and preventative sexual and reproductive healthcare results in fewer STI screenings and treatment as well as increased rates of poor pregnancy outcomes and infant mortality.

Healthcare providers play vital roles in promoting the health and wellbeing of individuals with IDD. They must equip themselves and this population with the necessary knowledge and resources to express safe sexual and reproductive practices. It is a provider's role to integrate sexual health screenings into healthcare visits and individualize every visit to each patient with effective communication and discharge information. They must utilize additional time for each

appointment, integrate outside resources, and collaborate with the patient and their caregivers.

Effective communication within the medical community as well as individualized

communication methods between health providers and their patient with IDD, will assist in

removing sexual and reproductive health barriers, subsequently ensuring reduced rates of adverse

sexual and reproductive health outcomes.

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