

## Different Opinions of Sexuality and Sexual Education in Individuals with Intellectual Disability: A Literature Review

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### ABSTRACT

Previous studies have found that individuals with disabilities are more than twice as frequently sexually abused than those without. Among various disabilities, intellectual disability is particularly challenging due to its nature, severity, and complexity. This article aims to explore different perspectives on sexuality and sexual education for individuals with intellectual disabilities (ID). It examines the viewpoints of parents, teachers, and the individuals themselves. To obtain a comprehensive understanding of the existing literature on sex education for people with ID and diverse opinions on the topic, a thorough evaluation of social science databases from 2015 to 2022 was conducted. The research sample comprised 14 articles. The review underscores the importance of collaboration among parents, teachers, and individuals with ID to establish an empowering and well-informed environment for sex education. It highlights the significance of using age-appropriate and accessible materials, promoting inclusivity, and establishing support networks. By addressing the specific needs of individuals with ID in sex education, we can enhance their overall well-being and foster a more inclusive society. It is crucial to encourage open and non-judgmental discussions, provide resources, and offer training to parents and teachers to ensure effective sex education for individuals with ID.

**Keywords:** *Sexuality, Sexual Education, Intellectual Disability*

The term intellectual disability refers to a significant impairment in understanding complex information, learning new skills, and functioning independently, which begins before adulthood and has long-term consequences on the development of an individual (Department of Health [United Kingdom], 2001). It is characterised by “significant limitations in intellectual functioning and adaptive behaviour that emerge prior to age 18” (AAMR, 2002). DSM-5 defines intellectual disabilities as neurodevelopmental disorders that begin in childhood and manifest as intellectual, social, and practical difficulties (American Psychiatric Association, 2013). The sexual rights, identity and needs of individuals with intellectual disabilities have been a hot topic among researchers, caregivers, and decision-makers for several decades now. However, it still remains to be a highly sensitive issue that is often disregarded and overlooked. Over the past few decades, the sexual rights and needs of individuals with intellectual disability have received increased

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Received: May 24, 2023; Revision Received: June 27, 2023; Accepted: June 30, 2023

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attention from researchers and policymakers, but it continues to be a highly sensitive issue that is frequently overlooked.

Sexuality has an important role in an individual's overall health and well-being and is one of the fundamental aspects of the human experience. It is a natural and fulfilling aspect of being human. Sadly, children and adolescents often lack access to comprehensive education on personal safety, sexuality, and reproductive health. This deprivation denies them the opportunity to engage in sexuality with dignity or to identify and report instances of sexual assault. Regardless of disabilities, young people experience emotions, have sexual desires, and long for intimacy. They deserve factual knowledge, discussions centred on values and responsible behaviour, and emotional support from adults to navigate their sexual lives responsibly.

Adolescents with intellectual disabilities, like other teenagers, experience a range of sexual and erotic experiences that neurotypical adolescents do. But they struggle to grasp genital and other tactile sensations, sexual function, and fertility status. Communication problems, a lack of understanding of what is considered appropriate behaviour, fewer options for privacy, and a lack of opportunities for appropriate sexual expression all contribute to the problem. Commonly inappropriate activities, such as discussing, revealing, or touching one's private parts in public, or touching the private parts of others, demonstrate a misunderstanding of what is public and private. It may expose children to sexual exploitation or labelling as a "perpetrator." Children with intellectual disabilities may believe that their actions are normal, and/or they may lack the understanding to give meaning to or interpret the actions of others. These children are also unable to share their knowledge and experiences in the context of sexual development, as well as the challenges they face in controlling their sexual behaviours, with those around them (Clatos & Asare, 2020). This can make it increasingly hard for parents, teachers, special educators and the individual itself to cope with and navigate the complexities of coming of age.

Previous studies have found that individuals with disabilities are more than twice as frequently sexually abused than those without. Among various disabilities, intellectual disability is particularly challenging due to its nature, severity, and complexity (Harader et al., 2009, Isler et al., 2009). Educational programmes that focus on sexual development are the need of the hour for these children and are a basic requirement. Persons with disabilities have the right to all knowledge about their bodies and how to function in society, regardless of severity, problems, or limit (Lakshmi H et al., 2011).

Although it is a well-known reality that they are more prone to be subjected to sexual exploitation and in dire need of proper sexual education, the reality of the situation is quite different, persons with intellectual disabilities are not given any kind of training about sex education just because of their disability (Lakshmi & Navya, 2015). Studies have found that 51.7% of adolescents with intellectual disability have not received any kind of professional education about sexuality. Almost 47% of them have never even discussed sex with their parents, implying that adolescents with intellectual disabilities have a lack of adequate information about sex and the stages of development during adolescence (Mercier et al., 1994).

Parents, teachers and other caregivers have a crucial role to play in the sexual education of adolescents, regardless of whether the child has intellectual disabilities or not. And, this

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ultimately affects how aware and comfortable the individual is with their sexuality. Because of their children's continuous reliance on them for assistance as they negotiate adulthood, parents' role in giving sex education to their children with ID maybe even more important. This is because, at a time when their peers without ID are gaining more independence, young people with ID are rarely offered opportunities to build their autonomy or social networks, spending a considerable part of their time under the supervision of adults (Cole & Cole, 1993).

Recognizing the significant influence of parents, teachers, special educators, and other caregivers in the lives of individuals with intellectual disabilities, it becomes crucial to acknowledge and value their viewpoints and insights regarding sexuality and sex education. However, we must go beyond that and prioritize the voices and perspectives of individuals with intellectual disabilities themselves, instead of suppressing their voices. Their active involvement and contributions are paramount in shaping discussions and decisions concerning their own sexuality and sex education.

By empowering individuals with intellectual disabilities to express their thoughts and preferences, we can ensure that their rights and needs are honoured, and they are actively included in conversations regarding their sexual well-being. This study aims to explore different perspectives on sexuality and sexual education for individuals with intellectual disabilities. It seeks to examine the viewpoints of parents, teachers, and the individuals themselves.

A comprehensive assessment of published literature in social science databases spanning the years 2015 to 2022 was conducted to provide a comprehensive overview of the existing research on sex education for individuals with ID. Fourteen research papers investigating the opinions of parents, teachers, and individuals with intellectual disabilities were identified and selected for review. By examining a range of sources, this study aims to gain a comprehensive understanding of the current discourse surrounding sexuality and sexual education in the ID population.

### ***Parents' Opinions***

Parents raising children with intellectual disabilities face unique challenges when it comes to advocating for their child's sexual needs. While there is no significant difference in gender when it comes to knowledge, attitude, and practice regarding sex education for individuals with intellectual disabilities, parents overall hold positive attitudes toward imparting sex education to their children (Nazli et al., 2022). However, they often feel confused and unprepared to navigate the complexities of their child's emerging sexuality (Stein et al., 2017; Kammes et al., 2020).

Sexuality education is seen as a proactive strategy, and parents play a primary role in providing this education. However, many parents feel unprepared to discuss sexuality with their adult children with intellectual disabilities, leading to avoidance of the topic altogether. Parents express a need to address stigmas around the sexuality of adults with intellectual disabilities and balance their child's independence with safety concerns (Kammes et al., 2020).

Mothers, in particular, play a crucial role as primary caregivers and must be educated and empowered about their child's sex education. They often experience anxiety and a sense of

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injustice regarding their child's challenging sexual behaviors. Lack of information and preparation further complicate their ability to address these behaviors, and they desire professional assistance in providing sexual health education and protection against abuse (Pryde & Jahoda, 2018; Kürtüncü & Kurt, 2020).

Providing sex education becomes a dilemma for mothers, as they fear that providing information about sex may intensify their child's desires and challenging behaviors. Their focus is on teaching appropriate behavior in public and private settings while monitoring and preventing escalating challenging sexual behaviors (Pryde & Jahoda, 2018; Kürtüncü & Kurt, 2020).

There is a deep-rooted fear among mothers that their child's sexual behaviors or behaviours perceived as sexual by others may limit their life opportunities and experiences. They express frustration over the incongruity between their child's cognitive abilities and their sexual development, acknowledging the possibility that their child may never have intimate relationships (Pryde & Jahoda, 2018).

### ***Teacher's Opinions***

Both parents and teachers recognize the importance of comprehensive sex education, acknowledging the need to address various sexual and cultural norms present in society today. However, it has been observed that certain topics, such as sexual and gender identities beyond heterosexuality, as well as masturbation, are often omitted from sex education curricula. This exclusion reflects a similar pattern seen in the literature concerning sex education for students with intellectual disabilities (Strnadová et al., 2022; Löfgren-Mårtenson & Ouis, 2018). These students are often considered too immature to learn about topics like homosexuality, bisexuality, or transgender rights, resulting in the erasure of sexual diversity among individuals with intellectual disabilities (Nelson & Odberg Pettersson, 2017). Teachers tend to adopt a heteronormative perspective, assuming their students with intellectual disabilities are heterosexual (Nelson et al., 2020). Religious beliefs may also influence the exclusion of masturbation from sex education, despite the fact that students with intellectual disabilities may engage in excessive and inappropriate masturbation, increasing their vulnerability to physical and verbal violence (Strnadová et al., 2022; Löfgren-Mårtenson & Ouis, 2018).

Furthermore, professionals face complexities related to cultural attitudes towards sex education held by parents and the limited understanding and management abilities of students with intellectual disabilities regarding different sexual norms (Nelson & Odberg Pettersson, 2017). Sex education often emphasizes the risks associated with sex while neglecting to address the positive aspects of sexual exploration and experience. Another concerning finding is that more than half of the teachers in the study reported instances of sexual abuse among their students with intellectual disabilities, indicating a higher prevalence compared to students without disabilities (Strnadová et al., 2022; Grove et al. 2018). Professionals expressed greater concern about sexual vulnerability and the risk of sexual assault within arranged marriages rather than inappropriate sexual behavior. They were cautious about creating anxiety for students caught between conflicting sexual and cultural norms upheld by schools and families (Löfgren-Mårtenson & Ouis, 2018).

Moreover, the perception and attitudes of male learners with intellectual disabilities towards women were influenced by media and local community observations, often perpetuating

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gender-discriminating behaviors, including violence against women (Chappell et al., 2017). The lack of adequate training and support for teachers leads them to rely on their own values and experiences when addressing sex education, which can be problematic if they fail to critically assess normative structures (Nelson & Odberg Pettersson, 2017).

Teachers employ various teaching practices and approaches, but they face challenges due to a lack of accessible resources, particularly for students with intellectual disabilities who have experienced sexual violence or who may be perpetrators themselves. Concerns were raised about the absence of available counseling in schools for students with intellectual disabilities who have been abused or neglected. Professionals expressed a lack of methods, knowledge, and strategies in effectively handling sex education for young people with intellectual disabilities. They faced uncertainties regarding the timing, delivery, and individuals responsible for sex education, particularly in addressing different sexual norms and values. The diverse needs and levels of intellectual impairment among this heterogeneous group contributed to professionals' indecisiveness (Löfgren-Mårtenson & Ouis, 2018; Chappell et al., 2017; Nelson & Odberg Pettersson, 2017). Additionally, students with intellectual disabilities are often not consulted regarding the topics they wish to be included in their sex education during their Individualized Learning Plans (ILPs) (Strnadová et al., 2022).

### ***Individual's Opinions***

Research conducted among young individuals with intellectual disabilities has revealed their curiosity and eagerness to learn more about sexual relationships, desiring experiences similar to their peers. They express a need to find companionship rather than solely focusing on sexual activity (Frawley & Wilson, 2016; Schaafsma et al., 2016). Despite facing barriers in accessing information, they possess a limited understanding of sexuality and relationships and display exploratory behaviour. However, they encounter challenges in finding, establishing, and sustaining relationships due to a lack of knowledge, support, and skills (Frawley & Wilson, 2016; Schaafsma et al., 2016; Azzopardi-Lane & Callus, 2015).

The prevalence of technology in today's age further complicates their navigation of romantic and sexual aspects, as negative reactions online are common. While some demonstrate coping skills in dealing with these issues, others may struggle (Schaafsma et al., 2016). Overall, they express a lack of information and opportunities to learn and explore, desiring facilitated discussions with peers rather than relying solely on parents or staff. The information provided to them is often mediated by parents and support staff and leaves them with unanswered questions (Frawley & Wilson, 2016; Schaafsma et al., 2016; Azzopardi-Lane & Callus, 2015).

Their educational experiences are gendered and predominantly heterosexual, focusing on rules, facts, and biology. However, this linear approach fails to meet their needs for a more explorative and chaotic engagement with sexuality and relationships (Frawley & Wilson, 2016). They also lack social opportunities to explore these aspects outside of regulated environments. Furthermore, sexual diversity is often overlooked, and caregivers may not be aware of the needs of homosexual individuals with intellectual disabilities. The predominant message conveyed to both young men and women is fear and concern regarding sex and sexual relationships (Frawley & Wilson, 2016; Schaafsma et al., 2016).

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The combination of limited education and information, along with a lack of private spaces for intimacy, makes it challenging for them to develop the necessary knowledge for safe, informed, and pleasurable sexual relationships. To enhance the sexual health of individuals with intellectual disabilities, it is crucial to prevent or minimize negative experiences. This involves promoting self-awareness, understanding personal needs, desires, and boundaries, as well as acquiring skills to protect oneself and engage in appropriate behaviour.

A critical literature review emphasises the need of offering inclusive and thorough sex education for people with intellectual disability. Both parents and instructors exhibit a willingness to engage in sex education sessions, but it is critical that they obtain sufficient training and support in order to build a healthy dialogue. To promote sexual health and well-being in this community, curricula addressing their special requirements, such as sexual and gender diversity, must be developed.

### CONCLUSION

A collaborative approach involving parents, staff members, and teachers is essential. This includes developing a partnership with individuals with intellectual disabilities, understanding their needs and wishes, and engaging in discussions that empower them to make informed decisions about their own bodies and relationships. Providing resources, materials, and support networks for parents, staff members, and teachers is also important in enhancing their knowledge and confidence in teaching sex education effectively.

Furthermore, it is crucial to use age-appropriate and accessible materials and to critically evaluate the content being used. By fostering open and non-judgmental conversations, promoting inclusivity, and offering support, an environment where individuals with intellectual disabilities feel empowered, informed, and safe in exploring their own sexuality can be created. Ultimately, by addressing the specific needs of individuals with intellectual disabilities in sex education, can increase their overall well-being and promote a more inclusive and supportive society.

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### **Acknowledgement**

The author(s) appreciates all those who participated in the study and helped to facilitate the research process.

### **Conflict of Interest**

The author(s) declared no conflict of interest.

**How to cite this article:** Raj, S. E. & Chavhan, P. (2023). Different Opinions of Sexuality and Sexual Education in Individuals with Intellectual Disability: A Literature Review. *International Journal of Indian Psychology*, 11(2), 2985-2992. DIP:18.01.293.20231102, DOI:10.25215/1102.293