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Review Article

Sexuality in intellectually disabled adolescents: The one who should not be named

Shyama Devi[1], Amisha Yadav[2], Manish Taywade[3]
[1]Assistant Professor, [2]Msc Nursing, College of Nursing, [3]Assistant Professor, Department of CMFM, All India Institute of Medical Sciences, Bhubaneshwar, Odisha, India

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Abstract

Approximately every third person of the world's disabled population is an adolescent, with 80% coming from developing nations, among which intellectual disability affects many adolescents. The prevalence of intellectual disability (ID) among adolescent children in India is 2 %.

Transition during adolescence is unique to each individual with ID, including physical, emotional, and sexual changes and is challenging for them due to insufficient intellectual capacity to understand these changes. They face a lot of challenges like adjustment issues to pubertal changes, sexual abuse, socially inappropriate behaviour, disturbed family dynamics etc. They are even hesitant to discuss their sexual practices with family members or care givers.

Belief in this misconception that encouraging sexual dialogues may make them a target of sexual violence or exploitation can lead to a reluctance to provide sexual health education to intellectually disabled youth. Strategies like effective transition planning, medical support during puberty, and education on sexual health tailored for adolescent children with ID may contribute to smooth sexual transitioning for these adolescents.

Key words:
Intellectual disability, Sexuality education, Adolescent sexuality, Adolescent health

Corresponding author: Mrs. Shyama Devi
Email: shyamadevi2501@gmail.com
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Introduction

In 2013, the term 'Intellectual Disability' was introduced as part of neuro developmental disorders, replacing the term Mental Retardation (Harris, 2014).

Following the World Health Organization (2014) definition, an Intellectual Disability is a significantly reduced ability to understand new

or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning) and begins before adulthood, with a lasting effect on development.

As per the United Nations report, approximately every third person of the world's disabled population is an adolescent, with 80% coming from developing nations, among which intellectual disability affects many adolescents (United Nations, 2022). In India, the prevalence of intellectual disability (ID) among adolescent children is 2% (Russell et al., 2022), which is significantly huge in number. These people have some special needs which can't be ignored.

Adolescents with ID are often perceived as being hyper sexual, inappropriately sexual, or having an impulse that is difficult to control. However, these adolescents experience sex in the same way their peers with no disabilities do (Woodard, 2004). Many still reject the idea that everyone has sexual wants, desires, and feelings regardless of physical or mental capabilities. For these kids to develop healthy sexuality, comprehensive sex education, interventions, and guidance are required. They are entitled to sexual health care, sexual education, and chances for socialization and sexual expression (Isler et al., 2009). However, they are kept devoid of even the basic sex education or cordial parental sex dialogue.

It is well beyond time to discuss sexuality with adolescents with ID, particularly those who live in developing countries such as India, where the term 'sex education' is in itself considered taboo.

This report provides a general overview of sexuality among adolescents with intellectual disabilities, including a review of the development of intellectually disabled and normal adolescents, puberty, sexual behaviour, contraception, sexual violence, and sexuality education issues specific to children and teenagers with intellectual disabilities and their families and suggestion for smooth sexual transition among adolescents with ID.

Comparison of sexuality among normal adolescents and adolescents with ID

There is no difference in pubertal changes, like age of onset, the intensity of symptoms, or the pattern of sexual behaviour observed between a normal adolescent and an adolescent with ID.

The physical pubertal changes in adolescents with ID is the same as in adolescent without it. As they grow, they develop more interest in their preferred gender to fulfill the need and desire to get connected to others and be loved (Yildiz and Cavkaytar, 2017).

Children with disabilities are more likely to feel socially isolated, miss out on opportunities to engage with and learn from their peers, and may be miss out on sexual exploration possibilities as well as sexual experimentation, social activities, and sexual experimentation (Murphy and Young, 2005). In contrast, most of their contemporaries receive this information about sexuality from peers, schools, open contact with parents, and social media. This lack of information and neglect results in socially inappropriate sexual behaviour among them.

Adolescent children with ID are more likely to experience sexual and behavioural issues and basic developmental health issues (Akrami et al., 2014).

The chance to establish independence and self-determination is frequently constrained in relationships of adolescents with intellectual disabilities. Their relationships are often marked by reliance on others (Löfgren-Mårtenson, 2004). Many young adults with

intellectual disabilities are accustomed to thinking that others have the best judgement, so they rarely question other people's choices. The relationship between family members and/or teachers and youth with ID is frequently very close and strong. When these people are willing to listen and provide support respectfully, there are better chances for young adults to form positive self-images. However, imbalanced relationships are common in many situations, and the needs of these individuals are often ignored, resulting in poor self-esteem and self-image.

Sexual development needs of adolescents with intellectual disabilities (ID)

Puberty is a stressful transition period that gets more complicated in adolescents with ID. They are hesitant to discuss their sexual practices with family members or caregivers because they are often taught that it is bad to have sexual desires. They can have trouble finding contraception and other sexual health products and services. Additionally, they might require reassurances to engage in fulfilling sexual relationships and specific guidance on how to do so. These concerns must be understood and assistance must be provided by educators, parents, and healthcare professionals (Isler et al., 2009). Some of the basic sexual development needs of an adolescent with ID are listed in the table below.

Teenagers with disabilities have specific needs related to their cognitive and physical issues in addition to needs similar to those of their peers in gynecologic health care (Quint, 2014). The needs for healthy sexual development of adolescents with ID are described below in Table 1.

Table 1. Sexual developmental needs of adolescents with intellectual disability

	10-14 years	15-17 years	18 and older
Sexual developmental needs	• Good and bad touch • Physical changes occurring during puberty • Menstrual and pubic hygiene • Acceptance of self (self-esteem) and others • Values, rights, culture, and sexuality	• Reproduction process • Family planning concepts • Contraception options available • Demonstration of the use of contraception with appropriate AV aid.	• Parenting skills • Vocational training • Economic independence • Concept of family and social institution

Issues related to puberty among adolescents with ID

Adjustment issues to pubertal changes

Transition during adolescence is unique to each individual, including physical, emotional, and sexual changes that are challenging for the person to comprehend and adjust to. Adolescents with ID are in a worse condition since they lack the intellectual capacity to understand these changes and what constitutes socially appropriate sexual behaviour.

The adjustment to these physical and hormonal changes is more difficult for adolescents with ID, especially for girls.

Adolescent girls with severe to profound ID may not even have a basic understanding of menstrual hygiene. This increases the risk of reproductive tract infections and other complications among them.

Sexual abuse

Adolescent Children with ID appear to be the most susceptible, and they are four to six times more vulnerable to be sexually abused than their counterparts without impairments (Wissink et al., 2015).

They are neither safe in foster care nor under their parents' care. Adolescent girls with ID are found to be more at risk of sexual abuse when compared to their male counterparts (Soylu et al., 2013). In more than 49% of cases, the perpetrator is a group member or peer adolescent, followed by people from the close or extended family, such as foster parents and foster siblings (immediate family) and uncles and grandparents (extended family) (Wissink et al., 2018; Yüce et al., 2009).

Socially inappropriate sexual behaviour

Adolescents with ID are restricted to a confined environment consisting of close family members, counsellors, teachers, etc. They often lack knowledge about social norms and values. When they are hit by puberty, they respond to it in a raw natural way which is often socially inappropriate.

According to instructors, educators, and school counsellors, masturbation in public places, such as schools, is one of the most prevalent sexual behaviours among teenagers. Furthermore, these teenagers exhibit genital views and show private areas of their bodies to others. The necessary knowledge to cope with these sexual activities in adolescents, how to control them, and educate them is lacking among teachers, school counsellors, and educators (Goli et al., 2022).

Disturbed family dynamics

Parents endure shame, prejudice, and the emergence of different, contradictory conceptions of disability based on biological and local religious, social, and cultural assumptions. Caregivers also carry a heavy load with little family or community support (Edwardraj et al., 2010).

Families with the child with ID face increased family burden (Maes et al., 2003). This burden, directly correlated with the severity of ID and takes the shape of perceived inadequacy, time constraints, emotional burden, physical hardship, economic burden, and social burden.

The lack of effort and the limited involvement of their partner is a major cause of separation among parents of children with ID. Families with disabled children have an increase in divorce rates of 5.97% on average (Risdal and Singer, 2016).

The family members often blame and shift the responsibility for the child's care to each other, resulting in neglect of the child and the

development of feelings of self-blame, worthlessness, and low self-esteem within the child with ID. These factors resist the smooth transition of the child during puberty.

Challenges

Parental challenges

Discussing sexuality with the child

While assisting the child with puberty, they frequently worry that:

(1) discussing sex may encourage sexual experimentation;

(2) they will not be able to manage queries responsibly; and

(3) the children may already know more than enough or very less about the topic.

They usually do not know at what age or ways to start these conversations. Even parents who talk about sexuality with their children do not spend enough time on these topics because they feel unprepared and ill-equipped for such conversations (Ashcraft and Murray, 2017; Berman et al., 1999).

Parents/guardians of disabled youth may fear that encouraging sexual dialogues may make them a target of sexual violence or exploitation. Belief in this misconception can lead to a reluctance to provide sexual health education to disabled youth.

Protecting the child from maltreatment

Parents fear any misconduct with the child, especially during and after the adolescent stage of the child. Hence, they try to reduce social interaction and limit visitors to the child as a defense mechanism. Keeping an eye on the child at all times is a tiresome job.

Adolescent related challenges

Children with ID and neuro-developmental disorders are 20 times more at risk than other children to undergo early puberty, also known as precocious puberty (Siddiqi et al., 1999).

This premature puberty can further burden socially immature children with disabilities by influencing an already disturbed body image and low self-esteem, exaggerating the difficulty of performing basic self-care and hygiene activities, and increasing the danger of physical/ sexual abuse and rape. True central precocious puberty in most females can be efficiently treated with gonadotropin-releasing hormone agonists (Owens and Honebrink, 1999).

Society related challenges

Cognitive limitations are not the only reason to be blamed for the adolescents with ID's limited understanding of and conceptualization of interpersonal relationships. It is nevertheless blamed on the effects of social exclusion and segregation, which continue to influence their day-to-day existence (Dimitrakopoulou et al., 2022).

Children diagnosed with ID are more likely to experience stigmatization and prejudice from society; for example, people without impairments are less likely to view them as romantic, sexual, or marriage partners and are more likely to accept them as colleagues or casual companions. (DeLoach, 1994) The restrictions of the handicap itself may not be the biggest obstacle to an adolescent's sexual development, but rather these kinds of societal and psychosocial impediments (Berman et al., 1999).

Gaps

A constant state of guilt

Most research studies indicate that adolescent children with ID uphold conservative views about sexuality and the dominance of negative feelings in this area (Lunsky and

Konstantareas, 1998). Specifically, adolescents with intellectual disabilities perceive sex as dirty and something they should not discuss (Dimitrakopoulou et al., 2022).

Experiences such as holding hands with the opposite sex, caressing, and kissing are perceived positively compared to intercourse or touching without clothes which is not treated with the same positive acceptance. Likewise, the practice of masturbation is evaluated negatively by 63% of adults with intellectual disabilities. In contrast, most adolescents without ID evaluated it positively (Timmers et al., 1981).

Where to seek knowledge from?

Compared to adolescents in the general population adolescent children with intellectual limitations have trouble finding knowledge about sexuality. This difficulty in access is also affected by their level of intellectual disability (mild or moderate). For teenagers with more severe intellectual disabilities, a more methodical approach is necessary for knowledge access and easy comprehension (McCabe and Cummins, 1996). Information should be provided through trained counsellors, dedicated clinics, friendly conversation with parents and teachers.

Lack of counselling and training centres for parents and caregivers

There are very few support and training centres for caregivers and parents of children with ID to train them in various aspects of the needs of adolescents with ID and their parents. They need to be trained to deal with the sexual aspects of their growing wards, initiate conversations, addressing their curiosity.

Strategies to improve sexuality in adolescents with ID

Transition planning

Individuals with special needs, their families, local service providers, school officials, and government staff who help youth transitioning to adulthood collaborate on transition planning. Transition planning is an interactive, dynamic process requiring multiple meetings to prepare, organize, and implement a successful transition for a kid with special requirements.

The objective of transition planning for youth with special needs is to find opportunities and experiences to help them better prepare for life as adults during their school years (Johnson et al. 2002). Transition planning can help kids find work, pursue post-secondary education, and engage in meaningful community life.

Support to families and other caregivers

According to caregivers, there has been a lack of support from that outside of the immediate family. They often undergo a lot of physical, mental, or financial stress in balancing the ID person's support needs with other responsibilities; hence, they should be regularly screened for and proactively attended to by care givers' support needs.

In studies involving parents of kids with intellectual disabilities, multiple measures of social support are taken into account. Additionally, it is a crucial practical consideration that parents might be particularly vulnerable to disrupting their informal support networks during their child's adolescence (Dada et al., 2020).

Inter professional team collaboration

Education, health, vocational training teams, and other sectors of society should come together to assist adolescents with ID in effective and smooth transitioning through different stages of life. These teams can cover various aspects of transitioning adolescents with ID resulting in a holistic development of the individual.

Medical support during puberty

Hormonal intervention is advised for girls with intellectual disabilities to relieve dysmenorrhea, abnormal bleeding, cyclic mood changes, or a combination of these symptoms, to help with menstrual hygiene, and to provide contraception. Menstrual manipulation can ease menstrual pain, regulate cycles, or reduce monthly menstrual flow.

Sexual health education designed for adolescent children with intellectual disabilities

Beneficial improvements were seen when people learned to articulate their demands better and behave in a more socially acceptable manner (Menon and Sivakami, 2019). Hence these kinds of tailored education programs should be encouraged. A few strategies to improve to sexual transition process are discussed below in Table 2.

Table 2. Strategies to improve the sexual transition process among adolescents with intellectual disability

Strategy	Innovations
Understand and address the complexity of the life of adolescents with ID and their parents	• comprehending family dynamics; • determining the degree of ID and the amount of knowledge; • fortifying communities; and • addressing relationship dynamics
Increase the availability of high-quality sexual health education.	• Addressing adolescent development • Accepting adolescent sexuality • Promoting healthy interpersonal interactions • Converging gender and rights
Utilize technology and media to engage youth.	• Developing entertainment education for intellectually disabled adolescents • Making computer and web based sexual health education understandable for teenagers with intellectual disabilities
Create a supportive policy environment.	• Encouraging best practices and evidence - based policy • Working at the community level • Making ARSH clinics accessible to teenagers with intellectual disabilities
Enhancing the accessibility of contraception and other sexual health services	• Fostering trusting connect ions between providers and teenagers • Promoting youth-friendly services • Providing services in alternative settings

Inferences

While sexual health education and communication approaches may differ, youth with impairments share the same rights as individuals without disabilities and need the appropriate knowledge and skills. The same legal rights to sexual health information as their peers apply to young people with disabilities. However, programs should be modified so that the data can be understood and taught in meaningful ways. Individuals with ID have the equal rights in consensual sexual relationships as others in the community. However, comprehending and giving informed consent to sexual activity can sometimes be more challenging.

Future directions

In recent years, there has been an ideological shift away from considering the sexual conduct of people with disabilities as abnormal or pathological. Despite this change in thinking, many people with disabilities struggle to express their sexual conduct at the appropriate time, place, and manner. They need adequate support and a conducive environment via a team approach to deal with it. Pediatricians are encouraged to discuss sexuality issues with children and adolescents on a routine basis, to protect the privacy of children and adolescents, to promote self-care and social independence among them, to strive for adequate sexuality education, and to offer training and instruction to families of kids and teens with learning difficulties. Intersectoral coordination should be used to improve support for parents and children with ID. Treatment for this behaviour has many important implications for these children's developmental, social, and educational outcomes and community integration.

The effectiveness of therapy for inappropriate sexual behaviour in adolescents and young children with developmental disabilities in India has not received much research. To improve our understanding of evidence-based treatments for inappropriate sexual behaviour, more methodologically sound research must be done.

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