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Sexuality of people with intellectual disabilities – a systematic review

Seksualność osób z niepełnosprawnością intelektualną – przegląd systematyczny

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Abstract

The sexuality of individuals with intellectual disabilities is a frequently overlooked topic, despite its significant impact on their lives and well-being. This paper presents a systematic review of existing research on this subject, using databases such as PubMed, Embase, and CINAHL. A literature search was conducted, identifying 10,037 studies, ultimately including 24 significant research papers that met the selection criteria, along with 14 supplementary articles. The aim of the review was to explore the issues related to the sexual functioning of individuals with intellectual disabilities, identify the most common barriers and limitations to healthy sexual fulfilment, and highlight the associated risks. The results of the review underscore the need for further research in the area of sexuality of individuals with intellectual disabilities. The analysed articles addressed various issues, such as inadequate sexual education, social and institutional barriers, diversity of needs and experiences, and social stigmatisation. The conclusions point to the necessity for a change in the approach to sexual education, increased social awareness, and the adaptation of support services to the individual needs of people with intellectual disabilities, which can contribute to improving their autonomy, safety, and quality of life. Ongoing research in this field and the implementation of practical actions are essential for the development of a more inclusive and understanding societal approach to the sexuality of individuals with intellectual disabilities. Only through such efforts can full participation of individuals with intellectual disabilities in society be ensured, along with respect for their rights to sexuality and intimacy.

Keywords: stigmatisation, sexuality, intellectual disability, sexual education, exclusion

Streszczenie

Seksualność osób z niepełnosprawnością intelektualną jest tematem często pomijanym, mimo że ma znaczący wpływ na ich życie i samopoczucie. Artykuł jest przeglądem systematycznym dostępnych badań na ten temat, opracowanym na podstawie baz danych PubMed, Embase i CINAHL. Przeprowadzono przegląd piśmiennictwa, identyfikując 10 037 badań, z których ostatecznie wybrano 24 istotne prace badawcze spełniające kryteria selekcji oraz 14 dodatkowych artykułów. Celem przeglądu było przedstawienie problemów związanych z funkcjonowaniem seksualnym osób z niepełnosprawnością intelektualną, zidentyfikowanie najczęstszych barier i ograniczeń w zdrowym spełnieniu seksualnym oraz wskazanie związanych z tym zagrożeń. Autorzy przeglądu podkreślili potrzebę dalszych badań w obszarze seksualności osób z niepełnosprawnością intelektualną. Analizowane artykuły poruszały różne zagadnienia, takie jak niewystarczająca edukacja seksualna, bariery społeczne i instytucjonalne, różnorodność potrzeb i doświadczeń oraz stygmatyzacja społeczna. Wnioski wskazują na konieczność zmiany podejścia do edukacji seksualnej, zwiększenia świadomości społecznej oraz dostosowania usług wsparcia do indywidualnych potrzeb osób z niepełnosprawnością intelektualną, co może przyczynić się do poprawy ich autonomii, bezpieczeństwa i jakości życia. Kontynuacja badań w tej dziedzinie oraz wdrożenie praktycznych działań mają zasadnicze znaczenie dla rozwoju bardziej inkluzyjnego i rozumiałego podejścia społecznego do seksualności osób z niepełnosprawnością intelektualną. Tylko w ten sposób można zapewnić pełne uczestnictwo tych osób w społeczeństwie oraz poszanowanie ich praw do seksualności i intymności.

Słowa kluczowe: stygmatyzacja, seksualność, niepełnosprawność intelektualna, edukacja seksualna, wykluczenie

INTRODUCTION

Sexuality is one of the fundamental aspects of human life, significantly impacting its quality and overall well-being. In a society where increasing emphasis is placed on individual autonomy, equality, and respect for human rights, the topic of sexuality of individuals with intellectual disabilities (ID) should not be overlooked. Despite growing social acceptance of diversity, the sexuality of individuals with ID remains under-researched and is often neglected in scientific inquiry and public discourse (Kijak, 2013).

According to the World Health Organization (WHO), “intellectual disability” is defined as a significant limitation in general intellectual functioning and adaptive behaviour difficulties, occurring before the age of 18 (World Health Organization, 1980). Approximately 1–3% of the global population suffers from ID, representing up to 200 million people. ID is much more prevalent in low-income countries, where it affects 16.41 out of every 1,000 people (Geukes et al., 2019). The criteria for mild, moderate, and severe ID are typically based on IQ scores and levels of adaptive functioning. These criteria are included in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the International Classification of Diseases, 11th edition (ICD-11).

Individuals with mild ID (intelligence quotient, IQ: 50–69) usually develop social and communication skills during the preschool years. They have minimal sensory-motor impairment and often achieve academic skills comparable to those of sixth-grade students. Adults with mild ID can generally live independently with minimal support and work in competitive employment settings. Individuals with moderate ID (IQ: 35–49) typically acquire communication skills in early childhood. They may need moderate support with daily living activities but are often capable of performing social and vocational roles in sheltered or supported environments. Individuals with severe ID (IQ: 20–34) have significant difficulties in communication and basic self-care skills. They require intensive support and supervision in daily activities. They can learn basic life skills but need lifelong support. Individuals with profound ID (IQ: <20) have extremely limited communication and functional abilities. They require constant support and supervision in all aspects of life, including basic self-care and healthcare (Boat and Wu, 2015; Seshadri et al., 2019).

The causes of ID are varied and may include genetic factors (e.g. Down syndrome, Klinefelter syndrome, Turner syndrome, Prader–Willi syndrome), biological factors (e.g. infections during pregnancy, hypoxia, malnutrition), and environmental factors (e.g. exposure to toxic substances) (Lee et al., 2023).

Down syndrome is the most common genetic cause of ID, occurring in about 1 in 700 births. It is characterised by the presence of an extra copy of chromosome 21, leading to delays in both cognitive and physical development. Individuals with Down syndrome have specific physical features,

such as slanted eyes with epicanthic folds, a flat facial profile, small ears, and a small mouth. The level of ID ranges from mild to moderate, and children with Down syndrome may need educational and therapeutic support throughout their lives (Akhtar and Bokhari, 2023).

Sexuality encompasses the ways in which individuals experience and express themselves sexually. This includes various aspects, such as biological, psychological, physical, erotic, emotional, social, and spiritual feelings and behaviours (Agocha et al., 2014). Major challenges in the sexual sphere for individuals with ID include limited access to sexual education, stigmatisation and marginalisation of needs, lack of autonomy and self-determination, exploitation and abuse, inadequate support and understanding, and difficulties in forming relationships (Ballan, 2012). Individuals with ID often lack access to appropriate educational programmes tailored to their needs and cognitive abilities. Most existing educational programmes fail to account for the specific requirements of this group, leading to difficulties in understanding their own sexuality, lack of awareness of boundaries in relationships, and challenges in handling situations related to the sexual sphere (Gougeon, 2009).

Individuals with ID frequently experience social isolation and stigmatisation, which hinders their full participation in both social and professional life. Negative stereotypes and prejudices can lead to a lowered sense of self-worth and difficulties in social integration. Increasing social awareness and promoting acceptance and inclusion of individuals with ID are essential steps toward reducing social exclusion (Ali et al., 2012). Individuals with ID often face limitations in autonomy and independence in matters related to their lives, including sexuality. Decisions regarding their sexual lives are often made by caregivers or institutional staff, limiting their ability to self-determine and make choices in this area. This, in turn, restricts their ability to fully express their sexual identity and fulfil their intimate needs (Skuban-Eiseler, 2022).

As mentioned earlier, individuals with ID are characterised by varying degrees of limitations in intellectual functioning, which can affect their ability to understand and evaluate situations and social interactions. Due to these difficulties, they are often more susceptible to manipulation and exploitation by others, including in the sexual sphere. Their limited ability to interpret situations and assess the intentions of others makes them easy targets for sexual abuse. They may have difficulty distinguishing between appropriate and inappropriate behaviours in sexual relationships (Tomsa et al., 2021).

Individuals with ID often struggle with a lack of acceptance and support from their families, friends, and social environment. This limited understanding can lead to a sense of isolation and hinder them from openly expressing their needs and desires, especially regarding sexuality. Facing these communication and social barriers, individuals with ID encounter difficulties in building and maintaining healthy, fulfilling relationships. The lack of appropriate support and

understanding of their needs can deepen the sense of exclusion and limit the possibility of full participation in social life, posing a significant challenge to their self-realisation and life satisfaction (Badcock and Sakellariou, 2022). Research on the sexuality of individuals with ID is important from both an individual and societal perspective. Addressing the needs of individuals with ID and striving to improve their functioning in the sexual sphere has a global dimension and should be a priority for policymakers. Such actions lead to better adaptation of support services and the creation of more accessible and appropriate sexual education programmes, contributing to the promotion of autonomy, safety, and dignity for this social group.

METHODOLOGY

This work is a systematic review. Searches were conducted in PubMed, Embase, and CINAHL (EBSCO). As of 2 April 2024, the search terms “sexuality”, “intellectual disabilities” in PubMed, Embase, and CINAHL yielded 1,412, 677, and 1,606 records, respectively. After narrowing the search to clinical studies, the number of records was reduced to 13, 403, and 137, respectively. Additionally, searching for “sexuality” and “disabled people” in PubMed, Embase, and CINAHL yielded 4,622, 469, and 1,251 records. Following the application of the clinical studies filter, the results were 106, 294, and 229, respectively. No time restrictions were applied to the analysis of articles, and only full-text, English-language manuscripts were included in the review.

OBJECTIVES

The aim of this review is to analyse existing research on the sexuality of individuals with ID, to present the key issues related to the sexual functioning of individuals with ID, identify the most common barriers and limitations to healthy sexual fulfilment, and highlight the associated risks.

SELECTION CRITERIA

The selection process included clinical studies on animal models and randomised controlled trials involving individuals with ID, where sexual behaviours were analysed. Case reports were also included. Studies that did not directly involve individuals with ID and their sexuality, such as those involving individuals with physical disabilities or diseases not affecting intellectual functioning, were excluded.

MAIN FINDINGS

The review included 24 records of varying quality and sample sizes, as well as 14 supplementary articles referenced in the introduction. The selected works are research studies that are statistically significant and directly relevant to the topic of sexuality in individuals with ID. The article selection process is illustrated by the PRISMA diagram (Fig. 1).

OVERVIEW

Six main themes related to the sexuality of individuals with ID were identified in the review: sexual education and sexual awareness, sexual activity and sexual health, personal and sexual relationships, support and interventions, sexual violence and sexual safety, institutional policy and practice.

Sexual education and sexual awareness

A study by Top et al. (2022) focused on assessing the sexual development of adolescent children with moderate to severe ID based on their mothers' perceptions. The study involved 127 children, with data collected through interviews and two tools: the Family Information Form and the Scale of Sexual Development Characteristics of Adolescent Children with Intellectual Disabilities. The results showed that nearly half of the mothers (45.7%) felt unable to provide sexual education, and 97.6% had no information on the subject. High scores on the scale suggest that mothers have insufficient awareness of their children's sexual development and treat the topic as taboo, leading to the avoidance of discussions about sexuality. A meta-analysis conducted by González et al. (2018) confirms the efficacy of educational sexual programmes tailored to the needs of individuals with ID. The results highlight that well-structured interventions with properly trained facilitators significantly enhance the participants' knowledge, self-awareness, and safety.

Another study, conducted by Oloidi et al. (2022), analysed the impact of social attitudes on caregivers' practices in supporting personal and sexual relationships (P&SR) of individuals with ID. It was found that caregivers face difficulties arising from public expectations and beliefs about people with ID. Key issues include socio-cultural norms significantly influencing caregivers' approaches to P&SR, often leading to neglect of these needs; gaps between policy and practice hindering effective P&SR support; and concerns about safety causing personal and sexual needs of individuals with ID to be neglected. The study highlights the need for improved policy and practical support in this regard.

Other researchers conducted a cross-sectional, observational study to examine the attitudes of Indonesian health science students toward the sexuality of individuals with ID. A total of 617 active undergraduate students in medicine, psychology, and public health at the University of Indonesia completed questionnaires. The findings indicate that individuals with ID often experience social stigma and exclusion in sexual contexts. Despite having the same sexual needs and desires as those without disabilities, they frequently encounter various physical and social barriers. The study emphasises the need for better sexual education, increased social awareness, and greater support systems to enable people with disabilities to fully participate in sexual life (Evlyn et al., 2021).

Another project aimed to explore the experiences of sexual education among young people with ID aged 16–21 in

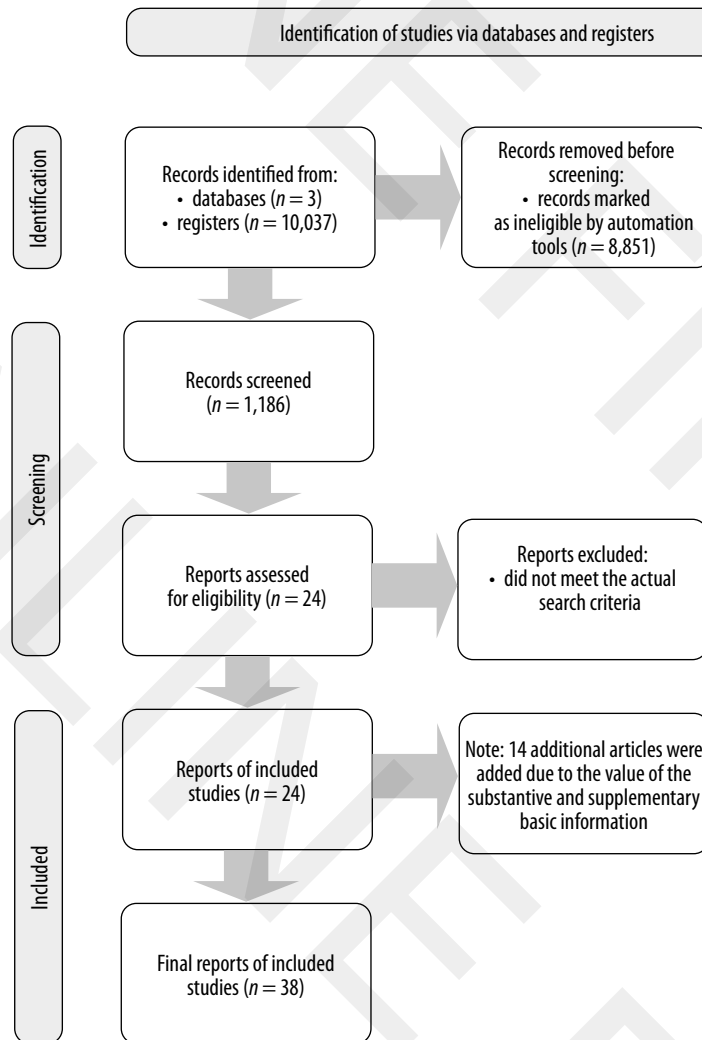


Fig. 1. PRISMA flow diagram of the study selection process. A total of 24 records were included based on inclusion criteria, and 14 additional articles were added as supportive literature

Sweden, and determine how this education is implemented. Qualitative interviews were conducted with 16 young individuals with ID. The results showed that current sexual education often focuses on risks and unwanted pregnancy, while neglecting aspects such as pleasure, desire, and intimacy (Kijak, 2018; Löfgren-Mårtenson, 2011). It was suggested that using critical pedagogy could be an effective approach for teachers in special schools, helping to develop appropriate models of sexual education that encompass all aspects of sexuality.

In contrast to the previously mentioned study, another group of authors focused on evaluating the effectiveness of an educational programme using the mastery learning model aimed at improving knowledge of sexual health and development among children with ID and increasing mothers' awareness of these issues. The research design involved 48 children, divided into educational and control groups. After implementing the educational programme, children in the educational group showed a significant increase in

knowledge about sexual health and personal development. Additionally, mothers of children participating in the programme increased their awareness of their children's health and sexual needs (Kurt and Kürtüncü, 2024).

A study by Schaafsma et al. (2016) aimed to assess the needs of individuals with ID in the area of sexuality. Partially structured interviews were conducted with twenty participants recruited through organisations providing services for people with ID and self-help groups. The findings showed that the sexual education received by participants was infrequent and of poor quality. Their knowledge of safe sex was mainly limited to contraception and sexually transmitted infections (STIs). The study emphasises the need to expand the scope of sexual education to include topics such as online relationships, social media, and parenting in order to better meet the needs of this group.

An alternative approach to sexual health and sexuality education was demonstrated in a study conducted on self-advocates, i.e. individuals advocating for themselves regarding

the sexuality of people with ID. Hole et al. (2022) identified a lack of support and adequate education from caregivers and professionals regarding the representation of sexual diversity and the inclusion of positive aspects of sexuality, such as communication and pleasure. Consistent with earlier studies, these findings indicate that individuals with ID often have limited access to reliable and comprehensive sexual education, leading to problems in identifying and expressing their own needs and limiting their ability to establish satisfying interpersonal relationships.

Sexual activity and sexual health

A project by Baines et al. (2018) conducted in England analysed the sexual activity and sexual health of young people with mild or moderate ID. The authors used data from a representative survey to explore various aspects of sexual life in this group. The study results showed that most young people with ID had sexual experience before the age of 19 or 20. Girls with ID were less likely to initiate sexual intercourse before the age of 16 compared to their peers without ID. However, both men and women with ID were more likely to engage in risky sexual behaviours compared to their peers without ID. Additionally, women with ID were more often pregnant and experienced motherhood, which may indicate a higher risk associated with reproduction in this group. The authors of the cited study conclude that there is a need to tailor educational and health services to the specific needs of individuals with mild or moderate ID. Another study assessed the effectiveness of a social skills training programme in improving interactions among individuals with ID. Participants with social anxiety and social skills deficits were randomly assigned to a 12-session dating skills programme or a control group. Social skills, knowledge about social and sexual situations, and the severity of social anxiety symptoms were assessed at baseline, after the programme, and after 8 weeks of follow-up. It was noted that programme participants showed a significant improvement in social skills and knowledge about social and sexual situations. Additionally, there was an increase in the frequency of interactions with people of the opposite sex. These results underscore the importance of tailored sexual and social education programmes for individuals with ID, as such interventions can significantly enhance their ability to establish healthy social relationships and increase sexual awareness (Valenti-Hein et al., 1994).

The concept of “positive sexology” in the context of people with disabilities regards the sexuality of individuals with ID as a natural part of their lives rather than a pathology. The aim of the following study was to explore the sexual lives of young adults aged 20–30 with ID and to evaluate the effectiveness of sexual education. Interviews were conducted with 18 individuals with profound ID who participated in occupational therapy workshops; none had previously received sexual education. A control group not subjected to any training was also included. The results showed

qualitative differences in awareness related to engaging in sexual intercourse. Those who had undergone training exhibited greater awareness and prudence in making sexual decisions. Regarding sexual preferences, the most common forms of sexual arousal were masturbation and genital intercourse. Before the training, condom use was very rare, but after the intervention, the number of people using contraception increased significantly. This study confirmed the widely accepted view that sexual education significantly improves sexual awareness and health of young adults with ID. In contrast to previous studies, researchers in this work focused on understanding the romantic and sexual experiences of individuals with moderate intellectual disabilities. Among the 142 participants surveyed, masturbation was the most commonly reported sexual behaviour (75.7%), while sexual intercourse was rare, and condoms were seldom used (Estruch-Garcia et al., 2024). Women more often reported cases of sexual abuse than men. The study also identified misconceptions about the risks associated with sexual intercourse and contraceptive methods. The conclusions from this study refer to the need to provide sexual education for people with moderate intellectual disabilities to promote healthy sexual experiences and prevent risky behaviours.

Conversely, a study by Jahoda and Pownall (2014) compared the level of sexual knowledge between teenagers with mild ID and teenagers without disabilities, showing significant differences in their sources of information. The study involved 30 teenagers with ID and 30 without disabilities. The results showed that teenagers without disabilities possessed a higher level of sexual knowledge. An interesting interaction between group and gender emerged: young women without disabilities better understood sexual issues than men, while in the ID group, men demonstrated more extensive knowledge compared to women. Both groups had misconceptions about sexuality and sexual health, with more frequent errors among participants with ID.

Personal and sexual relationships

Attempts to identify the characteristics sought in a partner by adults with ID were made by Bates et al. (2017). Interviews were conducted with 11 participants from the UK who had maintained a partnership for over a year. The results of the study showed that for people with ID, qualities such as love, kindness, and companionship are the most important in partner relationships, while less importance is attached to factors such as social status or intelligence. The study suggests that the expectations of participants regarding relationships are shaped by their experiences related to ID and the environment in which they grew up. Individuals with ID may experience social exclusion, have difficulty forming relationships with people outside their environment, and may have limited access to suitable meeting or dating opportunities. Additionally, they may face communication or social limitations that hinder

the building of satisfying partner relationships. These limitations can also be internalised by people with ID, negatively impacting their self-esteem and self-worth in the context of seeking a life partner (Bates et al., 2017).

Researchers in this field have focused on various aspects of the lives of adolescents with ID, such as self-identification, acceptance of one's disability, independence, building social and intimate relationships, knowledge about sexuality, and safety-related skills. The researchers conducted an intervention in the form of a structured group sexual education programme for adolescents with neurogenetic developmental disorders, comprising 10 sessions held every two weeks, for both the adolescents and their parents. Changes in the independent activity of adolescents with ID and their perception of the concept of "friendship" were assessed. The results indicate the necessity of implementing tailored educational programmes that improve social integration and help build healthy personal relationships (Plaks et al., 2010).

The perception of sexuality and social needs among young adults with ID was the subject of research by Australian scientists. The study participants described sexuality as a fundamental need, similar to that of individuals without disabilities. They expressed a desire for sexual opportunities and relationships, which contrasted with common social beliefs that often depict people with ID as asexual or having reduced sexual needs. Participants experienced rejection, concerns about acceptance, and a lack of confidence in whether they would have the opportunity to express their sexuality and form intimate relationships. They indicated that these limitations stem not only from their disability but also from a lack of support and resources from service providers, family members, and negative social attitudes regarding their right to express sexuality. This study highlighted the need for a change in societal attitudes toward disability and underscored the importance of redefining the perception of the rights, abilities, and needs of people with ID (Coulter et al., 2023).

Students in medical fields such as nursing, public health, emergency medical services, and physiotherapy were surveyed to analyse the relationship between their perceived model of ID and their subjective attitudes toward the sexuality of people with ID. The study used proprietary tools, including the Likert-type scale "Perspective of intellectual disability" to determine the disability model, as well as the Likert and semantic scales for the study of attitudes toward sexuality. The results showed significant correlations between the disability model and attitudes. Students who adopted the individual model of ID exhibited negative attitudes toward the sexuality of people with ID, perceiving their sexuality through the lens of deficits and biological limitations. On the other hand, students who adopted the social model had a more positive approach to the sexuality of people with ID, recognising it as natural and complex, similar to the sexuality of able-bodied people. The study emphasised the importance of assessing the sexuality of people with ID, drawing attention to the need to consider their emotional and relational needs (Parchomiuk, 2013).

Support and intervention programmes

The effectiveness of the "Positive Choices" educational programme was assessed in the context of young adults with ID. This programme was designed to promote healthy relationships, develop sexual awareness, and prevent sexual abuse among people with ID. It has been shown that participation in the programme significantly increases participants' knowledge about sexual education. Participants also gain greater awareness of safe relationships and the ability to recognise warning signs related to sexual abuse. The "Positive Choices" programme effectively contributes to improving the social and sexual competencies of people with ID, which is crucial for their safety and social integration (Graff et al., 2018). The findings of González et al. (2018) suggest that educational programmes should encompass not only the fundamental aspects of sexual health but also adapt their content to the specific needs of individuals with ID. Additionally, training for facilitators plays a critical role in ensuring effective communication and responsiveness to participants' needs (González et al., 2018).

Researchers are also focused on developing new tools and strategies to support professionals in communicating about sexual health with youth with ID. According to surveys conducted among professionals supporting people with disabilities, personal beliefs as well as the environmental norms and rules of institutions significantly influence how they communicate information about sexual and reproductive health to youth with ID. Professionals such as social workers, nurses, teachers, and programme administrators have different approaches and needs in terms of support and educational tools. Appropriately tailored tools and strategies can enhance professionals' competencies and improve the quality of sexual education offered to youth with ID, which is crucial for their sexual health and safety (Colarossi et al., 2023).

Unlike previous studies, Gutierrez-Bermejo and Jenaro (2022) propose introducing a sexual assistant to support people with ID. Their model enables individuals with ID to meet their sexual needs using an autoerotic and therapeutic approach, while excluding any form of sexual interaction between the assistant and the person with a disability. The study also emphasises the importance of adhering to the rights recognised in the Convention on the Rights of Persons with Disabilities and promoting continuous learning about sexuality. Sexual assistants provide essential behavioural support for people with ID, helping them meet their needs related to sexuality and develop healthy relationships. At the same time, the authors emphasise the need to monitor such interactions to prevent role confusion and minimise the risk of unhealthy emotional attachments to professionals. In terms of training and accreditation, the authors suggest that sexual assistants should be properly trained and possess basic knowledge of the social and health aspects of sexuality, as well as undergo additional specialised training related to disability, sexuality, and the

ethical aspects of sexual support. This model aims to ensure the high quality and effectiveness of the support provided (Gutiérrez-Bermejo and Jenaro, 2022).

Sexual violence and safety

The analysis of the impact of psychopathological symptoms on the ability of individuals with mental illnesses to protect themselves from HIV and other STIs by using condoms also revealed educational gaps. The study included 467 individuals with severe mental illnesses who were recruited from public psychiatric clinics in Rio de Janeiro and participated in an HIV prevention programme. The results showed that the severity of psychopathological symptoms had a significant impact on self-assessed ability to use condoms. More active individuals with elevated mood tended to have a better self-assessment of their ability to use condoms. In contrast, individuals with more severe negative symptoms, such as emotional blunting or social withdrawal, had poorer self-assessed condom use skills. People with mental illnesses may face difficulties maintaining sexual safety due to specific challenges related to their mental health condition, highlighting the need to consider different groups of patients when creating support programmes (Pinho et al., 2020). Although this project did not directly address individuals with ID, it illustrates the significant role that current mental health status plays in the ability to use available methods of protection against unwanted pregnancies and STIs.

Another challenge faced by individuals with ID is accessing reliable information about sexuality on the Internet, presented in an understandable form. Researchers note that young people with ID express a desire to engage in experiences similar to their peers without disabilities, including the possibility of exploring real relationships. Despite barriers to adequate sexual education, the study found that young adults with ID have the ability to independently acquire information, particularly using the Internet. Young women with ID negatively assess sexual education in schools, considering it insufficient and unhelpful. They often feel underinformed compared to their peers in mainstream education. Even participants from special schools report deficiencies in sexual education, despite needing it at a young age. The Internet proved to be a significant source of information, especially when understanding professional literature was challenging, although there was a lack of structured approach and moderation of open discussions on the topic. The authors also stressed that transitional programmes provided slightly better sexual education than schools, thanks to smaller group sizes and more accessible trainers (Frawley and Wilson, 2016).

An alternative approach to understanding education and safety focuses on the perceptions, experiences, and knowledge of individuals with ID regarding personal and sexual boundaries, as well as on identifying significant factors preventing sexual abuse. One such study, based on

semi-structured interviews, involved five women and two men aged 25 to 40, who expressed a desire to be in relationships but encountered difficulties such as receiving no responses on dating apps, participated. All participants had limited knowledge about sexuality and sexual boundaries, leading to misunderstandings and difficulties in defining sexual consent. Some participants experienced sexual abuse, both reported and unreported to authorities. They also described pressures to send nude photos and recounted traumatic experiences related to sexual violence, leading to long-term trauma and fear. These negative experiences had a significant impact on their mental health and overall well-being. The study highlights the need for improved protection and support for individuals with ID regarding sexual violence and safety, as well as the importance of education on personal and sexual boundaries. It also points to the need for more responsible practices in the context of online dating and psychological support for individuals affected by trauma related to sexual abuse (Svae et al., 2022).

Institutional policy and practice

There is very limited data on the actions taken by governments and relevant institutions to protect the sexual health of individuals with disabilities.

In the Netherlands, a study aimed to examine how issues related to sexuality and sexual rights are addressed in Individual Support Plans (ISPs) for people with ID. Researchers analysed the content of 187 ISP documents from seven different support service organisations. It was found that the majority of documents contained some references to aspects of sexuality, but these were mainly descriptive, lacking specific guidelines for providing professional support in this area. Information about sexuality in ISPs often consisted of general descriptions or passing mentions, without addressing specifics such as sexual education, ensuring sexual safety, or access to appropriate health services. In the context of sexual violence and safety concerns among people with ID, this lack of a comprehensive approach in ISP documents may lead to insufficient support in sexual matters and increase the risk of exposure to inappropriate behaviours or sexual exploitation. The study's findings underscore the need for a more detailed inclusion of these issues in ISPs, along with appropriate training for professionals working with individuals with ID, in order to improve the quality of services provided (Stoffelen et al., 2017).

SUMMARY

Research on the sexual education of individuals with ID and their sexual health underscores several significant issues and needs that require societal and institutional attention. Most studies indicate insufficient sexual education for individuals with ID and their caregivers. Parents of children with ID often feel ill-equipped to provide such education, due to various factors including a lack of appropriate

resources and support in the sexual development of their children. Furthermore, strong societal attitudes and beliefs regarding the sexuality of individuals with ID often lead to the neglect of their personal and sexual needs. Consequently, individuals with ID frequently experience stigma and exclusion concerning their sexuality. Despite having similar sexual needs and desires as their peers without disabilities, they encounter numerous physical and social barriers that hinder the development of fulfilling interpersonal relationships. In some cases, individuals with ID engage in risky sexual behaviours, such as unprotected intercourse, which increases the risk of unintended pregnancy and STIs. This is associated with low levels of knowledge about sexual health and limited access to contraception. Effective educational programmes can significantly improve the sexual health of individuals with ID, enhancing their awareness and competence in safe sexual practices. These programmes should accommodate the diversity of needs and abilities among individuals with ID. Additionally, support from professionals such as sexual assistants, along with well-prepared caregivers and healthcare professionals, plays a crucial role in improving the sexual health of individuals with ID. Implementing specialised educational programmes and tailored communication strategies is essential for fostering their social integration and supporting mental well-being.

Conflict of interest

The authors do not report any financial or personal connections with other persons or organisations which might negatively affect the content of this publication and/or claim authorship rights to this publication.

Author contribution

Original concept of study: KN, PP, JS, MP. Collection, recording and/or compilation of data; analysis and interpretation of data; writing of manuscript: KN, PP. Critical review of manuscript; final approval of manuscript: JS, MP.

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