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EDUCATION TO SUPPORT INTIMATE RELATIONSHIPS FOR YOUTH WITH INTELLECTUAL DISABILITIES*

Introduction: Treating a person with a disability in a personalized manner acknowledges their autonomy and supports their personal choices, privacy, and preferences. For young individuals with intellectual disabilities, this matter becomes more complex, especially when it concerns romantic and sexual experiences.

Research Aim: This review aimed to understand the barriers that adolescents with intellectual disabilities face in receiving appropriate sex education, i.e. education that supports their involvement in intimate relationships while being appropriate to their characteristics and needs.

Evidence-based Facts: There is a growing body of research indicating that many young people with intellectual disabilities experience difficulties in realizing their sexuality and face restrictions on their right to intimate relationships. They are also more vulnerable to abuse and risky sexual behavior because they often do not understand social rules and signals, cannot differentiate socially appropriate sexual behaviors, and have difficulties in negotiating equal relationships, setting boundaries, and reporting abuse. Literature also provides guidelines and proposals for actions to improve this important area of life for adolescents, highlighting the importance of implementing educational programs and preparing specialists and parents to engage in meaningful conversations with adolescents with intellectual disabilities about sexuality and intimate relationships.

Summary: Meeting the needs for closeness, sexual expression, and romantic activities of adolescents with intellectual disabilities can be managed in a safer and more intimate way. Education offers an alternative to ignoring, suppressing, interfering with, or treating this sphere of activity and experience as non-normative and forbidden.

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INTRODUCTION

Although progress is being made towards recognizing individuals with intellectual disabilities as autonomous and having the right to their bodies, the topic of intimate relationships is still neglected (Holland-Hall and Quint, 2017). An intimate relationship is defined here as “a relationship with another person that involves emotional and physical closeness, is consensual, and is considered romantic and/or sexual in nature by both parties” (English et al., 2018, p. 150).

Intimate relationships are not solely tied to sexual behaviors; they encompass more than just participation in sexual relations. Sexuality is recognized as an equally important aspect of life, crucial for development, quality of life, and well-being of all individuals (Friedman and Owen, 2017; Swango-Wilson, 2008). Similarly, initiating and maintaining intimate relationships serves essential purposes such as affiliation, comfort, safety, support, pleasure, and satisfaction (English et al., 2018; Isler et al., 2009; Retznik et al., 2021).

Intimate relationships are a fundamental right of all people and play a key role in shaping identity, attractiveness, self-confidence, and how we feel in our bodies (McDaniels and Fleming, 2018). Therefore, the rights of individuals with intellectual disabilities to form intimate relationships, marry, engage in sexual activities, and acquire knowledge about sexuality must be respected, protected, and realized based on pleasant, informed, and safe experiences (Holland-Hall and Quint, 2017; Schaafsma et al., 2015; Frawley and Wilson, 2016).

The topic of romantic and sexual relationship needs of individuals with intellectual disabilities has largely been ignored and treated as taboo (Healy et al., 2009; Rohleder, 2010) or presented as problematic (Friedman and Owen, 2017; Rowe and Wright, 2017). They have long been denied recognition of their abilities and support in expressing their sexuality, making choices about intimacy, relationships, marriage, and sexual activities in conditions of privacy and control over their bodies (McConnell and Phelan, 2022).

Efforts to suppress sexuality among individuals with intellectual disabilities historically included policies of forced sterilization, bans on marriage, and gender segregation in institutional facilities (Kijak, 2013; McDaniels and Fleming, 2018; Rowe and Wright, 2017). These practices of control and domination have not entirely disappeared and currently include “hidden or forced contraception” and discriminatory child care interventions leading to high rates of care removal (McConnell and Phelan, 2022, p. 2).

Individuals with intellectual disabilities were commonly perceived as asexual beings, “eternal children” incapable of sexual relationships, as well as vulnerable

victims or sexual deviants (Friedman and Owen, 2017; Jahoda and Pownall, 2014; Konieczna, 2010; Retznik et al., 2021). They were seen as needing protection and supervision, unable to make their own choices, and their sexual behaviors needed to be restricted or prevented (Friedman and Owen, 2017; Kijak, 2013). Although recent years have seen some progress in breaking these stereotypes and discussing practices of controlling sexuality within this population along with the idea of normalization, societal attitudes towards integration are changing slowly (de Wit et al., 2022; Rowe and Wright, 2017).

With the support of caregivers and specialists, many individuals with intellectual disabilities realize their sexuality and need for partnership in intimate and lasting relationships (Holland-Hall and Quint, 2017; Retznik et al., 2021). However, for the majority, this is not the case, and their experience becomes “forbidden love”, “mocked love”, “unfulfilled love”, or “platonic love” (Kijak, 2014, pp. 106–107). Love and the pursuit of intimate relationships and partnerships, forbidden by their environment (parents, staff of social welfare homes, or other support institutions), are suppressed and replaced by other forms of activities. In the case of mocked love, sexuality is also suppressed but additionally ridiculed by treating manifestations of sexuality as trivial, silly, or irrelevant, labeling individuals with intellectual disabilities as incompetent and childish. Unfulfilled love is characterized by caregivers, therapists, and parents assessing and deciding on partner meetings (how often, under what circumstances, in what place, and of what quality intimate contacts can be realized). In the case of platonic love, feelings are directed towards random people: rehabilitators, caregivers, therapists, teachers, fulfilling the need for romantic love without the desire or need for sexual satisfaction.

There is consensus among researchers and specialists that comprehensive sex education can enable individuals with intellectual disabilities to lead what is considered a normal life, experiencing satisfaction from activities and experiences in the realm of intimate relationships and sexuality (Schaafsma et al., 2015; Strnadová et al., 2021).

Although sex education is considered a human right and the best way to reduce many problems and improve the situation (including, for example, increasing awareness of their rights, reducing abuse, unplanned pregnancies, and sexually transmitted infections), adolescents with intellectual disabilities still do not receive appropriate sex education (Fornalik, 2020; Schaafsma et al., 2017). Numerous gathered evidence confirms the unpreparedness of adolescents with intellectual disabilities for adulthood, including insufficient skills crucial for functioning in the realm of intimate relationships (Strnadová et al., 2021).

RESEARCH AIM AND QUESTION

The aim of this review is to identify potential barriers that adolescents with intellectual disabilities face in receiving such sex education that would support their involvement in intimate relationships.

Findings from such a critical analysis and synthesis of literature can provide insights into what can be improved in the sex education of adolescents with intellectual disabilities and what is currently lacking. Researchers argue that developing effective programs begins with “mapping interventions” by studying the available literature (Schaafsma et al., 2017, p. 22, 24). Therefore, the first step towards real improvement requires assessing the needs and problems that can be addressed through sex education. This requires obtaining more information on what and how individuals with intellectual disabilities should be taught regarding relationships and sexuality (Schaafsma et al., 2017, p. 22).

EVIDENCE-BASED REVIEW

The importance of positive romantic and sexual experiences during the transition to adulthood

Adolescence and the transition to adulthood is a particularly sensitive developmental stage. The beginning of intimate and romantic relationships is one of the developmental tasks that mark a successful transition from childhood to adulthood (Retznik et al., 2021; Rowe and Wright, 2017; Strnadová et al., 2021). The ability to interact safely with strangers and develop meaningful relationships is essential for achieving a satisfying life and developing various adult roles conceptualized as community participation (McDaniels and Fleming, 2018). Employment is only one of the goals of the transition to adulthood (Konieczna, 2012). Equally important goals after leaving school include experiencing satisfying personal and social relationships, community engagement, and living with a partner and becoming a parent (Strnadová et al., 2022).

As young adults with intellectual disabilities transition to a broader range of social environments, including out-of-school institutions, adult groups, and workplaces, their ability to function socially is crucial for their success and safety in these environments (Konieczna, 2012). The opportunity to experience high-quality intimate relationships is often a key component of both personal and social adjustment in the adult world and a condition for health and personal well-being (McDaniels and Fleming, 2018).

On the other hand, there is a link between engaging in responsible, healthy, and acceptable sexual behaviors and living independently and safely in the adult community (Friedman and Owen, 2017; Strnadová et al., 2021). Lack of skills to establish appropriate sexual boundaries, initiate contact, and respond to others

in a socially appropriate manner can not only result in sexual exploitation and interpersonal conflicts but also lead to further exclusion from participation in various situations and relationships, both personal and work-related (McDaniels and Fleming, 2018; Rowe and Wright, 2017). It is important to recognize that aggressive sexual behaviors involving touch, exposure, and communication limit the social integration of individuals with intellectual disabilities, expose them to ridicule, legal conflicts, or non-acceptance by the community and stigmatization (Lockhart et al., 2009). Furthermore, increased ability to make choices and decisions regarding sexuality and intimate relationships enables them to be autonomous and agentic individuals and to exercise conscious control over their sexual behaviors in a responsible manner (Strnadová et al., 2021; Strnadová et al., 2022).

Barriers to experiencing positive intimate relationships for adolescents with intellectual disabilities

During adolescence, individuals with intellectual disabilities face the same challenges in the realm of sexuality and romantic relationships as their peers with typical intellectual development (Pieńkowska, 2021). Adolescents with intellectual disabilities generally express positive desires, attitudes, and expectations regarding intimate relationships, sexual activity, and marriage (Healy et al., 2009; Retznik et al., 2021). However, deficits in psychosocial and decision-making skills among adolescents with intellectual disabilities can profoundly impact their ability to form and maintain intimate relationships. These skills may lag significantly behind their physical maturity and sexual impulses (Healy et al., 2009; Holland-Hall and Quint, 2017).

Research has shown that adolescents with lower cognitive abilities report lower rates of condom use or other contraceptive measures (Schaafsma et al., 2017), as well as higher rates of unintended pregnancies and sexually transmitted infections (Frawley and Wilson, 2016). Reported problems in the sexual experiences of adolescents with intellectual disabilities include not knowing how to masturbate or masturbating in inappropriate places (Lockhart et al., 2009). Masturbation can be an appropriate outlet for sexual feelings and impulses, but adolescents with intellectual disabilities often express negative beliefs about touch and sexual activity as improper, dangerous, or forbidden, experience poor body image, and lower sexual satisfaction (Healy et al., 2009).

Young individuals with intellectual disabilities also exhibit higher rates of problematic sexual behaviors, including inappropriate romantic gestures toward others, sexual threats, inappropriate or suggestive statements, non-consensual touching, public displays of arousal, masturbation, or exhibitionism (Lockhart et al., 2009). Inappropriate sexual behaviors such as public nudity, public masturbation, improper handling of used menstrual products, and general lack of recognition and respect for personal boundaries can contribute to social discomfort and exclusion from social activities, and even involvement with protective services (Holland-Hall and Quint, 2017).

It has also been shown that adolescents with intellectual disabilities are more vulnerable to increased risk of sexual exploitation compared to their typically developing peers (Eastgate et al., 2011; Wissink et al., 2015). Consequently, young people are significantly more prone to mental health issues related to dysfunctional sexuality and abuse (Eastgate et al., 2011). This susceptibility to manipulation and sexual exploitation may stem from their desire for acceptance and conformity with peers and difficulty distinguishing appropriate and inappropriate physical contact. Moreover, documented evidence suggests that young people may lack the knowledge and communication skills needed to report abuse or fear the consequences of disclosing it (Miller et al., 2017). Adolescent boys with intellectual disabilities who have themselves been previously abused are at increased risk of committing inappropriate sexual acts (Wissink et al., 2015). Additionally, many individuals with intellectual disabilities are socialized into subordination, believing they lack sufficient authority to resist abuse. They may also feel worthless, undeserving of respect, accept their subordination as natural, and even perceive themselves as deserving of mistreatment (McConnell and Phelan, 2022).

Individuals with intellectual disabilities also report negative experiences concerning privacy and physical boundaries (Frawley and Wilson, 2016; Healy et al., 2009). They typically have limited opportunities for romantic and sexual exploration because they have smaller social circles than typically developing adolescents (Jahoda and Pownall, 2014), and engage in relationships with peers and romantic partners mainly under the supervision of staff or family (de Wit et al., 2022; Schaafsma et al., 2017). Furthermore, caregivers primarily encourage friendships instead of sexual relationships (Healy et al., 2009), and may impose strict restrictions on social interactions and sexual expression to mitigate risk of harm (de Wit et al., 2022; Holland-Hall and Quint, 2017; Lafferty et al., 2012; Schaafsma et al., 2017). Moreover, staff members may feel pressured to engage with sexual issues in an “interfering” manner. Studies have shown that couples were never left alone and, therefore, could not experiment with sexual behaviors. Difficulties also arose in finding an uninterrupted place to spend time together and getting to know partners outside of professional and school contexts (Retznik et al., 2021; Schaafsma et al., 2017).

Sex education offered to adolescents with intellectual disabilities

For the issues related to intimate relationships and inappropriate sexual behaviors described above, both formal and informal sex education is regarded as a primary intervention method (Holland-Hall and Quint, 2017; Schaafsma et al., 2015). Available education should be used to reduce reported problems and promote intimate relationships (McDaniels and Fleming, 2018). It aligns with the assumption that an adolescent may be more inclined to engage in inappropriate sexual behaviors and experience problems directly affecting the quality of social contacts if deprived of appropriate information and support in relationships and sexuality (Schaafsma et al., 2015). A low

level of knowledge can hinder the recognition of sexual exploitation situations, safe sexual practices, or the development of positive attitudes towards sexuality.

Although it has been recognized that many challenges can be overcome through better education and parental support (McGuire and Bayley, 2011; Schaafsma et al., 2015), the topic of sexuality is not discussed with adolescents with intellectual disabilities. This issue receives little attention in counseling, medical services, or interdisciplinary teams (Holland-Hall and Quint, 2017; McDaniels and Fleming, 2018). However, specialists and medical service providers are expected to routinely initiate conversations about sexuality, intimate relationships, and contraception directly with disabled adolescents and their caregivers (Holland-Hall and Quint, 2017; McGuire and Bayley, 2011). Despite these general recommendations, the fundamental question arises: how and from whom should a person with intellectual disabilities receive appropriate and substantive information about sexuality? (Krzemińska, 2019; McDaniels and Fleming, 2018). It is also worth asking: who and how should assess the level of sexual knowledge crucial for the safety of young people? (Holland-Hall and Quint, 2017).

The consequences of the mentioned lack of attention and resolution of responsibility for sex education are significant. A review of existing literature indicates that young people with intellectual disabilities, compared to their typically developing peers, show a low level of knowledge on topics related to sexuality, such as masturbation, pregnancy, safe sex, reproduction, and same-sex relationships (Healy et al., 2009; Swango-Wilson, 2011). They demonstrated only marginal and superficial knowledge about puberty, contraception, risks, or sexual hygiene (Frawley and Wilson, 2016; Isler et al., 2009; Jahoda and Pownall, 2014; Löfgren-Mårtenson, 2012; Schaafsma et al., 2017). Insufficient sexual knowledge results in these individuals being vulnerable to abuse or committing abuse, as well as exhibiting maladaptive socio-sexual behaviors such as violating others' personal space, inappropriate initiation of contact, and improper responses to others (Eastgate et al., 2011; Frawley and Wilson, 2016; McDaniels and Fleming, 2016).

Understanding sexuality and acquiring skills to cope with it, including making sexual decisions, is difficult to achieve based on media messages, information from friends, siblings, or the Internet, or by gaining experience through experimentation (Holland-Hall and Quint, 2017; Isler et al., 2009; Jahoda and Pownall, 2014; Schaafsma et al., 2017). Especially since the opportunities for learning in a natural educational and peer environment for a disabled teenager are limited due to isolation, and these experiences are often negative (Holland-Hall and Quint, 2017; Löfgren-Mårtenson, 2012).

Parents and direct care staff, due to the high level of support they provide to their charges, have many opportunities to be a source of information and support. However, reluctance among parents and caregivers to address their children's sexuality has been noted, which may stem from the fear that talking about sex could

potentially cause harm or encourage inappropriate sexual behaviors (Lafferty et al., 2012; Rohleder, 2010). Both groups express ambivalent and conservative attitudes (de Wit et al., 2022; Parchomiuk, 2009, 2013; Rohleder, 2010). One study found that only 2% of surveyed parents fully accepted their child's sexuality (Kijak, 2013). This fosters restrictive attitudes and behaviors towards offspring's activities related to this sphere (sexual intercourse, masturbation, viewing pornography). Similarly, professionals are not always ready to take supportive actions (Kijak, 2013). Studies have shown that a significant portion of staff holds conservative, non-progressive beliefs about the sexuality of individuals with disabilities and engages in many adverse actions, primarily denying, moralizing, but also restrictive and limiting. They may make efforts to thwart manifestations of sexuality among intellectually disabled individuals by substituting sexual activity with other forms such as recreational activities, prayer, physical or creative activities, listening to stories, and even using punishment (yelling, blackmail) or violence (Kijak, 2013, pp. 49–50; see also de Wit et al., 2022).

Furthermore, family members and staff usually do not initiate conversations on this topic or are not ready and prepared to handle sexual issues (Lafferty et al., 2012; Schaafsma et al., 2015). One study found that only 3% of professionals reported having routine conversations about sexuality with adolescents with intellectual disabilities or their caregivers (Colarossi et al., 2023). Only 39% of care facility staff reported conducting sex education (Schaafsma et al., 2014).

Some caregivers do not feel comfortable discussing sexuality, do not know how to start a conversation, and consistently express the need for support and assistance (Colarossi et al., 2023; Fornalik, 2014; McDaniels and Fleming, 2018). Educators (family and staff) also report a lack of preparation and confidence in discussing sexuality topics within the education of individuals with intellectual disabilities (Buchnat and Waszyńska, 2016; Holland-Hall and Quint, 2017; McDaniels and Fleming, 2018; McGuire and Bayley, 2011; Schaafsma et al., 2015; Schaafsma et al., 2014). Specialists also pointed to a lack of policies and clear guidelines in their service facilities (de Wit et al., 2022; Colarossi et al., 2023). They reported hesitating to plan activities and conduct discussions about sexuality when they did not see institutional support that would protect them from accusations of inappropriate behavior.

A significant barrier to providing equal access to sex education seems to be the erroneous perception by special education teachers of students as unprepared or incapable of assimilating content (Colarossi et al., 2023; de Wit et al., 2022; Fornalik, 2014). One study found significant discrepancies between teachers' perceptions of the benefits of sex education for students without intellectual disabilities, those with mild intellectual disabilities, and those with moderate to severe intellectual disabilities (Barnard-Brak et al., 2014). For students who did not receive sex education, the response "it is unlikely that students would benefit from such education" was indicated by 40% of teachers of students without intellectual disa-

bilities, 32% of teachers of students with mild intellectual disabilities, and as many as 75% of teachers of students with moderate or severe intellectual disabilities.

It should be emphasized that sex education for adolescents with intellectual disabilities, which contributes to increased knowledge and skills beneficial for health and safety, is also a matter of international human rights (Rowe and Wright, 2017). Nevertheless, numerous studies have shown that access to education, information, and appropriate curricula is insufficient for students with intellectual disabilities (Barnard-Brak et al., 2014; Jahoda and Pownall, 2014; McDaniels and Fleming, 2018). Researchers document the phenomenon of limiting children and adolescents' access to reliable education about sexuality (Fornalik, 2020; Kijak, 2013; Lewko, 2016; Parchomiuk, 2009). Moreover, it has been shown that adolescents with intellectual disabilities receive low-quality sex education and have fewer opportunities to learn about sexuality than their typically developing peers (Strnadová et al., 2021; Swango-Wilson, 2011).

Studies have also shown that most sex education programs lack an emphasis on maintaining knowledge and skills. Education was not provided regularly and continuously (Schaafsma et al., 2015). The frequency of sex education sessions was too low for the content to be absorbed (Strnadová et al., 2021). Additionally, individuals with intellectual disabilities should receive reminder sessions to reactivate acquired knowledge or skills (Schaafsma et al., 2017).

Furthermore, it has been noted that current sex education is typically conducted reactively in response to problems rather than as a tool to prevent issues and proactively support individuals with intellectual disabilities (de Wit et al., 2022; Friedman and Owen, 2017; Schaafsma et al., 2015). Researchers found that education was used in 92% of cases to reduce inappropriate behaviors (e.g. inappropriate masturbation, touching, victimization) and rarely emphasized social skills (Friedman and Owen, 2017). This is not insignificant as routine communication about sexual health is less prone to embarrassment than communication that is reactive (Colarossi et al., 2023).

Current sex education programs for adolescents with intellectual disabilities are criticized for being too conservative, overly restrictive, too narrowly focused on negative consequences, avoiding pregnancy, and safe sex practices, as well as relying too heavily on a heteronormative approach, and neglecting issues of positive relationships, intimacy, and sexual pleasure (Frawley and Wilson, 2016; Holland-Hall and Quint, 2017; Jahoda and Pownall, 2014; Löfgren-Mårtenson, 2012; McGuire and Bayley, 2011; Rowe and Wright, 2017; Schaafsma et al., 2017; Strnadová et al., 2021). Iva Strnadová and colleagues (2021) found that a common experience of students with intellectual disabilities was being warned by teachers about dangers in line with a "risk aversion only" approach instead of preparing them to navigate the world of intimate relationships safely, which are an important part of their extracurricular life.

Moreover, it has been found that conversations focusing solely on the negative aspects of sex can lead to internalized negative views on sexuality, contributing to negative sexual self-acceptance and lower self-esteem (Holland-Hall and Quint, 2017). It has also been shown that attempts to adapt existing sex education programs to the specific needs of individuals with intellectual disabilities were ineffective because the information was often unclear, euphemistic, or too technical (McDaniels and Fleming, 2018). According to some authors, when sex education is provided, it is not always well planned or sufficiently tailored to the specific needs of individuals with intellectual disabilities (Schaafsma et al., 2017). One of the barriers to effective sex education for individuals with disabilities is the use of inappropriate teaching methods and the lack of materials appropriate to the students' level of understanding, such as concrete examples, films, or visual aids (Colarossi et al., 2023; Barnard-Brak et al., 2014; Healy et al., 2009; McDaniels and Fleming, 2018; Rowe and Wright, 2017). It has also been noted that students with intellectual disabilities may lack the confidence and understanding to ask questions they are unsure about when discussing sexuality, which can pose an additional barrier during education (Schaafsma et al., 2017).

DISCUSSION

A critical analysis of the available literature allows for identifying the needs of adolescents with intellectual disabilities in the area of sex education and effective ways to reduce problems that can be solved through sex education.

Unfortunately, most of the reviewed studies did not provide detailed information on what was taught, why, and how individuals with intellectual disabilities should be taught regarding relationships and sexuality (Schaafsma et al., 2017). However, the available data indicates insufficient knowledge and skills among adolescents in various areas related to intimate relationships and sexuality (Strnadová et al., 2021). Several previous studies have shown that young people with intellectual disabilities demonstrated only marginal and superficial knowledge about relationships and sexuality (Frawley and Wilson, 2016; Schaafsma et al., 2017).

Therefore, researchers emphasize the need to identify potential barriers to implementing sex education (Pieńkowska and Izdebska, 2008). Also, it is essential to resolve the fundamental question of who could support and assist young people's intimate relationships (Krzemińska, 2019) and who is responsible and most suitable for teaching sex education (Pieńkowska and Izdebska, 2008; Schaafsma et al., 2017).

A literature review identifies several particularly significant barriers, such as social prejudices and cultural values, parents' attitudes towards their children's sexuality, gaps in professional staff preparation, and the lack of organizational policies and standards (Colarossi et al., 2023; Barnard-Brak et al., 2014; McConnell

and Phelan, 2022; Rohleder, 2010). These barriers may contribute to sex education being delivered reactively instead of being provided regularly and continuously throughout the education period and into adulthood, and by multiple stakeholders (Frawley and Wilson, 2016; Schaafsma et al., 2014).

Sex education should be particularly important and crucial for those involved in designing real support offerings for young people with intellectual disabilities, especially during high school or the transition to adulthood after graduation. Although professionals consider that conversations about sexual health and intimate relationships with adolescents with intellectual disabilities are not within their competence and recognize their personal lack of knowledge and training in sexuality, everyone integral to designing support for this population during their adolescence has a unique opportunity to initiate conversations to identify potential knowledge gaps among students and develop interventions and individual teaching programs (Holland-Hall and Quint, 2017; Isler et al., 2009; McDaniels and Fleming, 2018).

Researchers also emphasize that sex education must be treated as “another skill that needs to be taught” within individual educational programs developed in many countries worldwide for students receiving special education services (Barnard-Brak et al., 2014, p. 93; see also Strnadová et al., 2021). However, research based on a large national sample of students with intellectual disabilities in public schools in the United States found that issues of sexuality, love, and intimacy were not included in such programs, significantly reducing the chances of receiving sex education (Barnard-Brak et al., 2014).

Moreover, Australian studies analyzing the experiences and preferences regarding sex education of girls with intellectual disabilities aged 13 to 20 unexpectedly found that students were not active participants in meetings concerning education planning, even though students’ “individual education plans” should be prepared by all interested parties, including students, and meetings with specialists within “joint planning” should also be a space to discuss any necessary adjustments and educational preferences (Strnadová et al., 2021; Strnadová et al., 2022). Some surveyed adolescents did not know what this document was or its purpose, reported that no one had shown them this document, invited them to meetings, or prepared them to participate in such a meeting, and rarely were they asked by teachers what they wanted to learn in sex education classes. Importantly, such a service system that does not support the development of students’ self-determination contributes to increasing the risk of harm, including sexual abuse (Strnadová et al., 2022). Similarly, parents are not encouraged to engage in the support planning process within the development of individual education programs and to collaborate with special education teachers to discuss parents’ and students’ preferences and expectations regarding discussed topics, conducting sex education in mixed groups, and the gender of the person leading the program (Strnadová et al., 2022).

Researchers also suggest that specialists (e.g. doctors) can better support parents during conversations with adolescents about sexuality at home by providing parents with educational materials and information about available services (McDaniels and Fleming, 2018). They can also collaborate with staff providing direct care in facilities. A consistent approach to developing sex education programs for students with intellectual disabilities is needed, where support strategies should include students' and parents' wishes and preferences, consult with them on topics related to sexuality, and develop partnerships (Schaafsma et al., 2017). Developing a sense of agency and self-determination through students' and their parents' involvement in developing individual education plans should be more broadly incorporated into school practices (Strnadová et al., 2021). Teaching strategies should be individualized, with an emphasis on ensuring the accessibility of sex education through the use of visual support and accessible language (Strnadová et al., 2021).

Furthermore, sex education, like any other area of educational content, should cover a wide range of topics and not focus solely on risks and avoiding unwanted pregnancy (Holland-Hall and Quint, 2017; Löfgren-Mårtenson, 2012; Pieńkowska and Izdebska, 2008; Rowe and Wright, 2017; Schaafsma et al., 2017). Especially the omission or neglect of topics related to intimate relationships is a significant argument for the need to develop a more comprehensive sex education program (Strnadová et al., 2021).

Importantly, more programs should focus on social skills because a key issue related to sexuality is ensuring the ability to properly assess and cope with appropriate social challenges and relationships (McDaniels and Fleming, 2018). Lack of awareness of what behaviors are considered inappropriate, lack of ability to make healthy choices about sexuality and relationships, and insufficient knowledge of social norms (e.g. closeness, appropriate touch, expressing emotions related to rejection) expose young adults to the risk of unwanted attention or abuse and can complicate relationships with peers at work, in group living situations, or in the community (McDaniels and Fleming, 2018; Strnadová et al., 2021; Swango-Wilson, 2011).

Besides systematically conducted sex education in schools, there is a lack of available counseling for students with intellectual disabilities who have been abused or have been perpetrators (Pieńkowska and Izdebska, 2008; Strnadová et al., 2022). Teachers must also know how to report abuse cases to the appropriate authorities.

CONCLUSIONS

High-quality education in relationships and sexuality for individuals with intellectual disabilities, especially proactive, accessible, holistic, and participatory education, is undoubtedly a significant challenge (McDaniels and Fleming, 2018;

Parchomiuk, 2009; Strnadová et al., 2021). The role of specialists and doctors is unclear, there is a lack of cooperation between specialists, special educators, and parents, and the responsibilities of schools, pediatricians, and direct staff in providing intellectually disabled adolescents with necessary sexual knowledge and related social skills are not defined (Colarossi et al., 2023; McDaniels and Fleming, 2018). It is primarily expected that parents take on the role of sexual educators (Isler et al., 2009), but guidelines and support for parents have not been developed (McDaniels and Fleming, 2018). Moreover, it is forgotten that those implementing sex education need continuous support (Strnadová et al., 2022).

Given the discrepancy between current policy and practice regarding the prevention and sex education of adolescents with intellectual disabilities (McGuire and Bayley, 2011), the challenges related to accessing high-quality sex education for this group can only be overcome through collective efforts and cooperation from all involved parties. It is suggested that sex education should begin in the family and be continued in school as a formal sex education program supported by healthcare professionals (Buchnat and Waszyńska, 2016; Isler et al., 2009).

The paper presents the issue of supporting the intimate relationships of adolescents with intellectual disabilities along with several suggestions for possible solutions. Lack of education is one of the biggest barriers to safer socially acceptable sexual behaviors (Fornalik, 2020; Schaafsma et al., 2015; Swango-Wilson, 2008). Lack of education or its low quality leaves individuals with intellectual disabilities who need support in intimacy issues unequipped with the skills and understanding needed to develop intimate relationships.

To increase awareness of this important and largely unresolved issue, future research and broad discussions about prejudices and stereotypes towards individuals with intellectual disabilities and sexuality are needed. They can affect the readiness of specialists and parents to implement sex education and adopt an approach to intimate relationships based on the right to have pleasant and safe sexual experiences free from coercion, discrimination, and violence (Strnadová et al., 2022).

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EDUKACJA WSPIERAJĄCA RELACJE INTYMNE MŁODZIEŻY Z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ

Wprowadzenie: Traktując człowieka z niepełnosprawnością w sposób podmiotowy, wyrażamy zgodę na rozwój jego autonomii i wspieramy jego osobiste wybory, prywatność i preferencje. W przypadku młodego człowieka z niepełnosprawnością intelektualną sprawa ta nie wydaje się taka prosta, zwłaszcza jeśli dotyczy sfery romantycznych i seksualnych doświadczeń.

Cel badań: Celem niniejszego przeglądu było zrozumienie barier, jakie nastolatki z niepełnosprawnością intelektualną napotykały w otrzymywaniu odpowiedniej edukacji seksualnej, tj. takiej która wspierałaby ich zaangażowanie w relacje intymne, a jednocześnie byłaby adekwatna do ich cech i potrzeb.

Stan wiedzy: Rośnie liczba badań, które ukazują, że wiele młodych osób z niepełnosprawnością intelektualną doświadcza problemów w realizacji swojej seksualności i ograniczenia prawa do intymnych relacji. Jest również bardziej narażonych na nadużycia oraz ryzykowne zachowania seksualne, ponieważ nie rozumie zasad społecznych i sygnałów od innych, nie odróżnia społecznie odpowiednich zachowań seksualnych i ma trudności w negocjowaniu równych relacji, stawianiu granic oraz w zgłaszaniu nadużyć. W literaturze spotykamy także wskazówki i propozycje działań na rzecz poprawy tego ważnego obszaru życia nastolatków, jakim są związki intymne. Przy czym szczególnie podkreślane jest znaczenie wdrożenia programów edukacyjnych oraz przygotowania specjalistów i rodziców do angażowania się w znaczące rozmowy z młodzieżą z niepełnosprawnością intelektualną na temat seksualności i relacji intymnych.

Podsumowanie: Zaspokajanie potrzeb bliskości, ekspresja seksualna, aktywność romantyczna nastolatków z niepełnosprawnością intelektualną może odbywać się w bardziej bezpieczny czy intymny sposób. Edukacja stanowi alternatywę dla ignorowania, tłumienia, ingerencji lub traktowania tej sfery aktywności i doświadczeń jako nienormalnej i zakazanej.

Słowa kluczowe: relacje intymne, nastolatki z niepełnosprawnością intelektualną, edukacja seksualna



