



## REVIEW ARTICLE / ПРЕГЛЕДНИ РАД

# Risky sexual behavior of people with developmental disabilities and prevention

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## SUMMARY

The paper analyzes the results of studies that have explored the causes and prevention of risky sexual behavior in individuals with developmental disabilities.

The importance of the chosen topic lies in the fact that sexuality is one of the fundamental dimensions of human existence, which is influenced by biological, psychological, socio-economic, cultural, ethical, religious, and other factors.

Recent studies suggest that risky sexual behavior, including unprotected and unsafe sexual relationships, result from a lack of appropriate prevention and education programs, limited access to healthcare information, misunderstanding of instructions and safety warnings, difficulty communicating with healthcare professionals, inadequate societal care, and a lack of self-esteem.

The authors of the studies analyzed recommend that the content of preventive programs be adapted to individuals with developmental disabilities, in order to develop appropriate attitudes toward sexuality and a sense of responsibility for one's own health and the health of a partner. Providing informational brochures and guidelines on sexual health and the consequences of risky sexual behavior tailored to the reading abilities of people with developmental disabilities would improve accessibility and increase the quality of healthcare services.

Involving parents in empowerment programs and providing timely information about their children's sexuality and sexual health, as well as encouraging children with developmental disabilities to participate in conversations with parents about these sensitive topics, can have a positive impact on preventing risky forms of sexual behavior.

**Keywords:** developmental difficulties and disorders; sexuality and risks; information about sexuality

## INTRODUCTION

As a topic significant for their overall functioning, the sexual life of people with developmental disabilities has been at the margins of researchers' interest [1, 2, 3]. The sensitive nature of this topic and methodological barriers have also contributed to neglecting this research field. A significant number of studies focus on appropriate sexual behavior, with special emphasis on children with autism spectrum disorder and intellectual disability [4]. Risky sexual behavior is considered a significant factor affecting reproductive and overall health in young people. It is the cause of teenage pregnancies, sexually transmitted infections, sexual victimization, and other adverse health effects [5, 6].

Various factors can influence the occurrence of risky sexual behavior. They can be divided into environmental and personal factors, but are always interrelated. The most important environmental factors include, but are not limited to, the availability of psychoactive substances, poor financial situation, unemployment, inadequate connection with the community, a family history of problematic behaviors (e.g., alcohol and substance abuse, domestic violence and abuse), problematic behavior of peers the person interacts with, social isolation, and school failure [6, 7]. Personality traits are closely

related to substance abuse and, thus, low self-esteem, emotional problems, and developmental disabilities belong to the group of factors associated with engaging in risky sexual relations. The likelihood of risky sexual behavior is much greater when multiple risk factors are present simultaneously, such as low self-esteem, developmental disability, associating with peers who exhibit problematic behaviors, substance abuse, etc. [7].

Young people with developmental disabilities are characterized by significant variability, and regardless of this, they are at greater risk of engaging in behaviors that may further endanger their health [8]. Social psychological factors, namely identity, affect and coping style, are inextricably entwined with sexual behavior and, thus, sexual health outcomes [9]. When they begin exploring their sexuality, people with developmental disabilities face numerous challenges in accessing information and support. Usually, what is "accessible" to them is a set of "rules" that emphasize gender norms, focus on heterosexuality, and convey the message that sex and sexual relations are something to be afraid of [10].

The paper analyzes the results of studies that have investigated risky sexual behavior and the prevention of risky sexual behavior in individuals with developmental disabilities. The Consortium of Serbian Libraries for

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Coordinated Acquisition (KoBSON) and Google Scholar's Advanced Search tool were used to search and review the research. The search was conducted using the following terms in Serbian and English: sexual behavior, risky sexual behavior, prevention of risky sexual behavior, and individuals with developmental disabilities.

Considering the heterogeneity of the population with developmental disabilities, 30 papers published in the last five years and available in full text were selected and analyzed. In order to gain a more comprehensive understanding of the selected topic, the results of studies published before 2020 were also included in the analysis.

## **RISKY SEXUAL BEHAVIOR OF PEOPLE WITH DEVELOPMENTAL DISABILITIES**

The lack or inaccessibility of information about sexuality, difficulties in accessing reproductive and sexual health institutions, as well as myths and prejudices, significantly influence the formation of beliefs that developmental disabilities negatively affect the sexual and reproductive lives of people with these disabilities [11, 12]. A significant number of individuals with developmental disabilities are sexually active [13, 14]. At the same time, a large percentage of these individuals are exposed to various risks, such as sexually transmitted diseases, unintended pregnancies, sexual violence, etc. [12, 15]. In addition to the lack of knowledge, information, and healthcare support, risky sexual behavior of people with developmental disabilities is predominantly determined by their psychosocial characteristics, lack of self-esteem, and low levels of social skills [16].

The study conducted by Touko et al. [15] states that people with developmental disabilities more often engage in unprotected and unsafe sexual relationships than typically developing participants, and are more exposed to sexually transmitted diseases. The research focused on premature sexual activity, awareness of protective measures, knowledge of sexually transmitted diseases, and human immunodeficiency virus (HIV). By comparing the sexual behavior of individuals with motor disabilities and typically developing young individuals 15–16 years of age, Maart and Jelsma [17] found no significant difference in the prevalence of various forms of risky behavior between these two groups. The sample of participants with motor disabilities included 91 students, a quarter of whom were sexually active. Some had engaged in sexual activities at a younger age, had multiple partners, and did not use protection. In addition, many believed that there was no risk of getting HIV through sexual activity and, thus, felt no need to protect themselves or others, which indicates that, considering their overall health and level of independence, they are often at greater risk of contracting sexually transmitted infections.

The incidence of different types of risky sexual behavior and involvement in the system of services provided by centers dealing with the consequences of HIV were examined in a sample of young individuals with visual impairment, hearing impairment, and motor disabilities [18].

The results show that almost half of the participants were sexually active, that they rarely used protection against unintended pregnancy and sexually transmitted diseases, that one-third of the participants had sexual relations with multiple partners at a younger age, and that the participants with hearing impairment used the services of HIV centers more often.

Risky sexual behavior of young people with visual impairment is associated with the lack of appropriate preventive and educational programs, as well as the inaccessibility or unavailability of healthcare institutions and services [19]. People with visual impairment report difficulties in accessing information and disparities in access to health screenings, but they believe that healthcare institutions do not play a primary role in providing information on these topics [20, 21, 22], which is consistent with the results of studies that have examined this topic in samples of young people without visual impairment [23, 24, 25]. The sexual experiences of young blind people and young people without visual impairment are similar; however, the fact that blind people have limited access to health information indicates that there is a need to provide them with information brochures and guidance on sexual health and behavior in a reading medium appropriate to their needs [26]. A Brazilian study that aimed to examine how blind individuals contact rehabilitation professionals, as well as their level of awareness and knowledge about sexuality, reproductive and sexual health, and HIV and AIDS, determined that they lack knowledge about the transmission and prevention of sexually transmitted diseases, which is directly related to their limited education access [27]. This limitation may be associated with the professionals' unpreparedness to confidentially and effectively address the needs of individuals with visual impairment and communication barriers. Neglecting the rights of women with visual impairment regarding their sexual and reproductive healthcare is a significant finding of some studies, indicating that these women often do not know where to obtain information on sexuality-related topics [28]. Research on a sample of blind adults showed that physical attraction and the material status of partners played a secondary role for them during adolescence. Emotional maturity and qualities that are "not visible to the eye" but are crucial in life were the most significant [29].

Alongside risky sexual behavior, we can also discuss certain aspects of sexual abuse experienced by children and young people with visual impairment. Kvam [30] compared the frequency of reporting sexual abuse between individuals with visual impairment 18–65 years of age who lost their vision before the age of 18, and a group without visual impairment. The results showed that the participants with visual impairment reported sexual abuse more frequently and that the consequences of the abuse were serious.

The position of individuals with visual impairment can often lead to prolonged suffering, failing to report sexual abuse, and engaging in risky behaviors. Their dependence on caregivers helps the perpetrator, who is often a close person, to have control over the victim. People with visual

impairment may internalize negative societal attitudes, such as discrimination and stigmatization, leading them to lose self-esteem and blame themselves, which, together with the fear of abandonment (losing a “caregiver”), keeps them in abusive relationships [31].

For many years, the sexuality of people with intellectual disability was viewed as a societal issue, and eugenic goals focused on the need to protect society from their supposed deviance and promiscuity [32]. The studies on the sexual lives of individuals with intellectual disability are highly varied and include the following findings: that they are sexually active; that most, especially women, lack sexual activity; they generally lack knowledge about the use and effects of contraceptives; that they are victims of sexual harassment more often than their peers without intellectual disability; that they have a higher prevalence of unintended pregnancies, sexual abuse, and exploitation [33–36]. Interestingly, studies that found them to be sexually active also emphasized that emotional closeness with another person is of primary importance to them [36]. People with mental health problems are also a risk group, since they do not practice safe sex due to their limited knowledge about the use of contraceptives and financial difficulties [37].

## PREVENTION OF RISKY SEXUAL BEHAVIOR

Protecting the reproductive and sexual health of young people with developmental disabilities involves developing awareness of the potential consequences of risky behaviors. The content structure of prevention programs should aim to impact knowledge acquisition, healthy attitudes toward sexuality, and a sense of responsibility for their own health and the health of their partners [38]. Knowledge about the potential consequences of irresponsible behavior, unintended pregnancies, and sexually transmitted infections is a prerequisite for taking responsibility and making the right decisions about engaging in sexual activities [39].

Relying on superficial information from peers or the media and not knowing the consequences of risky sexual behavior can cause serious problems for young people with developmental disabilities [40]. Although parents of children with developmental disabilities state that they lack information about sexual and reproductive health and do not know where to seek necessary guidance [14], it is essential to emphasize their important role in educating their children about sexuality and all its domains from the earliest age. Sexual and reproductive health education is considered a priority for young people with disabilities, as they still receive little or no formal sexual health education [19, 39]. The joint responsibility of families and schools is to provide support in growing up, recognizing human values, and enabling children and young people to develop their potential to face various challenges, which can often lead to multiple adverse consequences. For example, it has been found that blind adolescents consider informational and emotional support from the education system extremely important and that they expect teachers to provide them with future-oriented information.

In addition, special support is expected to be provided to both students and parents [41]. However, the sexual health of young people with disabilities remains a “blind spot” in health promotion. This claim is supported by the fact that research on this topic often focuses on priority interventions, which should be based on needs, specifically, the need for sexual health education. The role of special educators is often not recognized. However, they can be key partners, as they understand disability and possess specific skills that make them suitable to be involved in the various stages of intervention [42]. Conversations about the consequences of risky sexual behavior conducted by well-informed parents have a positive influence and reduce the percentage of young people who enter risky situations [43]. Parental support and interest in all aspects of their child’s development positively affect the timing of first sexual relationships and avoiding risky sexual behaviors. When parents avoid this topic, adolescents seek information from unreliable sources or follow advice from peers, which sometimes, though unintentionally, encourages risky sexual behavior [5, 43].

Nowadays, social media provides easy access to information on various topics. However, after the family, school is the most important factor in acquiring knowledge and developing attitudes about sexuality and safe sexual behavior [40, 43]. Through different programs, the education system should warn young people about the consequences of engaging in risky sexual relations at an early age [44]. In collaboration with other professionals, teachers should create reliable and structured training programs on sexual and reproductive health, and implement them through panels, seminars, and workshops for children of different ages [25]. For example, Glumbić [45] recommends that sex education programs be highly individualized – that is, adapted to the specific needs of an individual with autism and their family; to respond appropriately, we must understand the function of a particular behavior; any activity we undertake should be consistent with the legal and customary norms and cultural characteristics of a given community; additionally, any sex education program should be implemented within the broader context of learning social skills and socially acceptable behaviors. In contrast, the findings of Wazakili et al. [16] show that topics such as infidelity, promiscuity, alcohol use, sexual abuse, and risky sexual behavior are not discussed within the family environments of persons with physical disabilities 15–24 years of age. The participants stated that most of them had participated in rehabilitation that focused on their physical disability, while the issues of sexuality and prevention measures against HIV were not addressed. The authors believe that rehabilitation professionals should make an effort to include sexual and reproductive health issues as part of their work with young people with disabilities [16]. The healthcare system should provide individuals with developmental disabilities with programs or forms of support on sexuality and the consequences of risky sexual behavior [14]. Stekić [46] determined that people with visual impairment 20–40 years of age have insufficient knowledge about sexually transmitted diseases, which raises a relevant



question about how they can protect themselves and recognize disease symptoms. Whether sex education is necessary for young people with developmental disabilities is no longer in question. The professionals are increasingly considering the education methods and contents to equip these young people with essential communication and decision-making skills, as well as help them become assertive and learn to say “no” when needed [45, 47]. Neglecting the need for sex education and the lack of appropriate healthcare access can result from stigma regarding the characteristics of sexuality (asexuality, hypersexuality) of young people with disabilities and not recognizing their needs, which violates their fundamental rights [45].

The National Program for the Preservation and Improvement of Sexual and Reproductive Health of Citizens of the Republic of Serbia ensures that sexual and reproductive healthcare is accessible to everyone, without distinction, and that their sexual and reproductive rights are respected. The same regulation emphasizes the significance of programs aimed at enhancing the sexual and reproductive health of marginalized and socially deprived groups, both locally and nationally, highlighting collaboration among healthcare institutions, local self-government units, and associations, along with including their representatives [48]. Networking community resources and sharing information in the process of creating educational programs and providing support are crucial for people with developmental disabilities in fostering a responsible attitude toward themselves and others [49]. Community resource lists should be made available to people with developmental disabilities, their parents, caregivers, and teachers as they represent important factors in achieving their well-being [50].

## CONCLUSION

Sexuality as an indispensable part of human identity has long been neglected when it comes to people with developmental disabilities. This was mainly due to numerous stereotypes and prejudices, such as that these people are not interested in romantic or love relationships, that they have no sexual urges, or that their sexual needs are deviant. Numerous factors that affect sexuality and risky behaviors in the typical population (biological, psychological, socio-economic, cultural, ethical and religious) intertwine much more complexly in people with developmental disabilities. A considerable number of these individuals are still denied their rights to sexuality and to sexual, intimate and partner relationships in various cultural environments. Based on studies conducted in countries that differ in cultural,

ethical and religious influences on young people, it is hard to conclude their overall contribution to forming attitudes toward sexuality and finding strategies to meet their sexual needs without becoming victims of risky sexual behavior that could adversely affect their health and social acceptance. Studies comparing the sexual behavior of individuals with various developmental disabilities with that of adolescents with typical development showed different results with regard to different types of risk behavior. Developing awareness of the potential consequences of risky sexual behavior and implementing measures to protect the sexual and reproductive health of people with developmental disabilities is one of the most significant challenges of modern society. The implementation of such a serious task requires a general strategic framework and accompanying secondary legislation that sets the structural and functional standards for the education of all persons involved in the issue of sexual health of people with developmental disabilities. It is imperative to familiarize people with developmental disabilities with the consequences of early sexual intercourse, the risks of unplanned pregnancy and the consequences of sexually transmitted diseases, as well as protection against abuse of the position of dependence on the help of others, usually close people. Sexual education and harmonization of educational approaches for individuals with various developmental disabilities, continuous work with parents and access and availability of information are key factors in the prevention of risky sexual behavior of individuals with developmental disabilities

A comprehensive analysis of research focused on patterns of risky sexual behavior among different categories of individuals with developmental disabilities, with respect for regional and cultural specificities and a comparative evaluation of preventive measures applied at national levels, could significantly contribute to a deeper understanding of this complex issue.

**Ethics:** The authors declare that the article was written in accordance with ethical standards of the Serbian Archives of Medicine as well as ethical standards of medical facilities for each author involved.

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## Ризично сексуално понашање особа са сметњама у развоју и превенција

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### САЖЕТАК

У раду су анализирани резултати студија које су се бавиле узроцима и превенцијом ризичног сексуалног понашања особа са сметњама у развоју. Значај изабране теме огледа се у чињеници да је сексуалност једна од темељних димензија људског постојања, на коју утичу биолошки, психолошки, социоекономски, културолошки, етички, религијски и други фактори.

Резултати новијих студија указују на то да је улазак у сферу ризичног сексуалног понашања, односно у незаштићене и небезбедне сексуалне односе, последица недостатка одговарајућих превентивних и едукативних програма, ограниченог приступа информацијама о заштити здравља, неразумевања инструкција и безбедносних обавештења, отежане комуникације са запосленим особама у здравственим установама, недовољне бриге друштва и недостатка самопоштовања.

Препоруке аутора анализираних студија су да садржај превентивних програма буде прилагођен особама са сметњама у развоју, да омогући формирање правилних ставова према сексуалности и осећаја одговорности за сопствено здравље и здравље партнера. Обезбеђивање информативних брошура и упутстава о сексуалном здрављу и последицама ризичног сексуалног понашања, који могу да задовоље читалачке могућности особа са сметњама у развоју, олакшало би доступност и подигло квалитет здравствене заштите. Укључивање родитеља у програме оснаживања и правремено информисање о сексуалности и сексуалном здрављу њихове деце, као и охрабривање деце са сметњама у развоју да учествују у разговорима са родитељима о овим осетљивим темама, могу позитивно утицати на смањење ризичних облика сексуалног понашања.

**Кључне речи:** сметње и поремећаји у развоју; сексуалност и ризици; информисаност о сексуалности