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# Adolescents with Intellectual Disability and Sexuality Matters: opinions, experiences and needs

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## ABSTRACT

The present review analyzes sexuality activities of adolescents with Intellectual Disability. The term «Intellectual Disability» was introduced in 2013 as part of neurodevelopmental disorders, replacing the term «Mental Retardation». The onset of this situation happens during children's growth. According to the World Health Organization (WHO), sexuality constitutes infeasible part of human's personality, it is a basic need and constitutes part of human nature, without however differentiate it from the other parts of life. Sexuality is of vital importance on adolescents' life with Intellectual Disability, who are capable to develop parts of sexual behavior according to society's rules while additionally adolescents may desire, append, and maintain interpersonal relationships. Worries and needs of adolescents with Intellectual Disability referring to sexuality activities are not differentiated on their base from these of general population. The history of sexual education for disabled people worldwide, has characterized from disuse, distortion, and tolerance. The analysis of data concerning sexuality and sexual behavior of adolescents with Intellectual Disability, as these are presented in bibliography, indicates the need of sexual education programs to be organized, with parallel information and counseling of their families. This review's findings aspire to constitute stimulus for the scientific and social recognition and elevation of the phenomenon of misprision of sexual awakening of adolescents with Intellectual Disability, as well as of the phenomenon of discrimination and exclusion. It, finally, aims at apprehending people with Intellectual Disability as individuals with sexuality, acceptable from the society.

**Key Words:** *Intellectual Disability, Adolescent, Sexual Activities or Behaviors*

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## Introduction

According to DSM-5, «Intellectual Disability» is a neurodevelopmental disorder, replacing the former term of «Mental Retardation». The background of Intellectual Disability is the existence of impairments in mental ability with an impact on the adaptability of the individual in cognitive, social, and practical level (1,2,3). According to the World Health Organization (WHO), sexuality is an integral part of every individual's personality, as a basic need, and an aspect of human nature, while cannot be separated from other aspects of life (4).

The term «sexuality» is often equated with the term «sexual intercourse», with sexual intercourse to be a substantial part of sexuality, no other way around (5). Sexuality in people with disabilities raised concerns due to uncontrollable childbearing. In the past, the sterilization of «defective» people was mandatory, which included «mentally ill, mentally retarded, epileptic, criminals, syphilitic, alcoholics» (6). There was a belief that motor or mental disability was combined with other disabilities, for instance sexual (7). Sexual evidence was a common habit in families with individuals with intellectual disabilities, keeping their adolescents in infantilism state (8,9).

Adolescence is the age when the body «awakens» and sexuality is expressed more intensely than in any other period of life, as an expression of the hormonal «explosion» that follows the hormonal calm of childhood (10). The physical (puberty), cognitive and psychosocial changes are many and the needs of the adolescent are related to the acceptance and management of these changes (10). Dating, exploring physical sexual activity and spending significant time in a romantic relationship are elements of a developing sexuality during adolescence (11).

According to the social model of disability, it is important to keep in mind that whatever title, characterization, diagnosis, or syndrome has been attributed to a person, who is human being after all. One should not focus solely on meeting the needs arising from a particular diagnosis or classification, such as «intellectual disability», but invest time in listening to the individual, to know and understand the person in general (12). Providing comprehensive support to these individuals means supporting the individual in all aspects of his or her personality.

The present study examines worries, needs, and attitudes referring to sexuality activities of adolescents with intellectual disabilities, not only those of adolescents but also of their parents, siblings, and society.

## Material and Method

In this review, qualitative research was conducted based on literature review, data analysis and findings of older studies, concerning individuals' attitudes toward sexuality of adolescents with Intellectual Disabilities. Very little information is available about people with disabilities in general and their own sexual needs. The subject of research is usually the perceptions and opinions of parents, teachers, support staff and not the young people with mental disabilities themselves. Vidalaki and her colleagues posed the following question: «which voices are silenced, and which ones determine the needs of people with a disability?». As physically intact we decide on the lives of our fellow human beings with mental disability, in absentia (13).

According to Dimou's research review in 2008, a total of 35 surveys were identified worldwide that investigated issues of sexuality of people with intellectual disabilities. Regarding their sexuality, the number of surveys identified was limited to 11, of which two took place in Greece (14). Of these surveys, four were conducted since 1973 to 1986, three surveys conducted during the period 1994-1999 and the remaining four conducted after 2000. The results of the above findings are going to be referred and analyzed in the present review.

## Results

The findings of the studies concerning sexuality issues, could be divided into three main categories. The adolescents' perspectives, the parents' perspectives, and the society's perspectives.

The first four studies conducted since 1973 to 1986 in the USA, surveyed self-perception, sexual ethics, knowledge about sexuality issues in adolescents with intellectual disabilities, as well as the attitudes of their parents, highlighting the lack of information and misinformation on these issues (14).

Concerning the first category, adolescents' perspectives, it is important to be mentioned that in terms of their attitudes on senses such as «love», «marriage», and

and «having family», the knowledge of adolescents was differentiated according to gender stereotypes, while it was strongly influenced by the family's socio-educational level (14).

The three main studies conducted since 1994 to 1999 concerning attitudes of adolescents with intellectual disabilities on sexuality issues, showed that adolescents with Down syndrome have the ability «to develop aspects of sexual behavior in accordance with the community's rules» (14). Additional research on sexuality issues in adolescents with Down syndrome, in comparison with their parents' attitudes, showed limited sexual knowledge of adolescents, conservative attitudes of parents regarding the sexual interactions of people with intellectual disabilities, but receptivity in terms of their children's sexual education (15,14). The presence of sexual experimentation was indicated too.

Comparing adolescents with intellectual disabilities with adolescents from the general population, it is important to mention that people with intellectual disabilities appeared to have the least sexual experience and the least experience in communicating with the opposite sex (16,14).

The experiences of intersexual coexistence of these adolescents are like those of the general population (14). Although their knowledge was incomplete, however, adolescents could absorb the knowledge provided to them about sexuality (17).

People with intellectual disabilities who participated in sexual education programs did not develop negative behaviors (premature sexual stimulation, unwanted pregnancy) as some were feared. On the contrary, positive changes were observed as individuals learned to better express their needs and behave in a more socially acceptable way (18).

According to the above studies, people with intellectual disabilities and/or autism were able to know the place and manner of proper sexual expression, while through sexual education; the incidence of sexual exploitation of these individuals was reduced (19).

Most research showed that adolescents and adults with intellectual disabilities maintained conservative attitudes toward sexuality and that negative emotions about sexuality predominate (20). Specifically, adolescents with intellectual disabilities «perceive sex as dirty and something they should not talk about» (14). Experiences such as «holding hands» with the opposite sex, «caress» and «kissing» were evaluated positively compared to «intercourse» or «touching without clothes» which were

not treated with the same positive acceptance (21,22). Likewise, the practice of masturbation was evaluated 63% negatively by adults with intellectual disabilities (21), while in contrast, it was evaluated positively by the majority (22).

The limited knowledge of the mentally disabled regarding the understanding and conceptualization of interpersonal relationships, did not attribute cognitive limitations, but attributed the consequences of social segregation and exclusion, which was continuing to shape their daily lives (14). Furthermore, it has stated a difficulty of adolescents with intellectual disabilities in accessing knowledge about sexuality compared to adolescents in the general population. This difficulty may be due to some differences in adolescents' knowledge of the level of intellectual disability (moderate or mild), as for adolescents with more severe intellectual disabilities the access to knowledge and its understanding presupposes a more methodical process (23).

Concerning the parents' perspectives in terms of sexuality issues, it was found that parents, siblings, or supervisors of adolescents with intellectual disabilities had the belief that the manifestation of sexual behaviors of those persons, even if it was happening with differentiated expressions in relation to the social whole, was of great importance for their emotional growth and balance, while they insisted on the positive effect of sexual intercourse on adolescents' self-perception (24,14). Furthermore, it was found a low level of sexual knowledge, conservative attitudes on the part of adolescents and an «overprotection» tendency by their parents, while parents did not present particularly formed attitudes on the above issues in the majority (14).

The parents of people with intellectual disabilities considered it important to talk to their children about sexuality issues, providing the formation of a more positive attitude towards sexual education, although they considered of this as a difficult process, as some issues, such as self-satisfaction, are still taboo (5,25).

Nowadays parents show a more positive attitude towards the sexual education of their children and have an essential role in their sexual education; however, they stated that they do not know the proper way and time to talk to their children about this issue (26).

The parents of people with intellectual disabilities seemed to realize the importance of sexual education in the way people with disabilities can understand, identify, and attempt to express their sexuality. Also, they have realized that their own role in this direction is equally

helpful and that with the proper education and help from competent services, they would be able to understand even more but also to support their children's effort to discover their sexual behavior (18).

Concerning the third category, society's perspectives and European research has sought to determine whether institutions support or cover the sexual self-identification of people with intellectual disabilities. In Germany, the historical review showed that people with intellectual disabilities have been treated primarily with taboo behaviors. However, in recent years, the acceptance of basic human rights in relation to sexual issues seemed to be shaping up by their support staff (27).

### Discussion

Research data showed that the wakening of sexuality of adolescents with intellectual disabilities and the lack of information about sexual issues were associated with a variety of negative and harmful consequences. The concerns and needs of adolescents with intellectual disabilities on sexuality issues were not differentiated fundamentally from those of the general population (28).

As it concerns adolescents with intellectual disabilities, McCabe (23) stated that adolescent boys mostly choose to be educated about sexuality by their friends. This could be explained as a result, perhaps, of the lack of effort from parents or of the absence of school as a source of information in this field. This fact, however, is dangerous for adolescents with intellectual disabilities as they may not be informed properly, as it involves risks of misinformation or transmission of incomplete knowledge.

On the other hand, the isolation, the ignorance, and the lack of sexual education that was imposed on people with disabilities could lead to inappropriate or irresponsible sexual behavior. The reason is that they didn't have the opportunity to learn to behave according to the social rules, with respect to themselves and to their partner. Furthermore, the lack of knowledge may lead individuals with intellectual disabilities to be sexually abused from the others (29).

An additional risk for people with intellectual disabilities was that of sexual harassment and abuse. The rates of these people being sexually abused - often by other people with disabilities - were dramatically high. However, this problem is not solved by complete abstinence from sexual activity, but by proper information and education, adapted to the mental level

of each child (30).

Concerning society's responsibilities to protect and support people with intellectual disabilities, sexual education has as its main concern to provide correct and valid information in matters of health education. It aims to cultivate respect, primarily for oneself and consequently for others, to inform on prevention and responsible behavior, to educate in issues of family planning and in general to expand the quality of learners' life. In recent years, apart from sexual education, other terms have also been used such as intersexual relationships, or interpersonal education. This new terminology may wish to broaden the scope of sexual education and to reduce the notion of «sexual» (31).

Sexual education in Greece is not yet included in the curriculum of formal education, therefore there is a lack of valid information of Greek adolescents about basic issues of sexuality (32). Similarly, sexual education is not included in the education of adolescents with special needs (intellectual or other disabilities).

The difficulties in implementing and introducing sexual education programs extend to special education to a greater extent. The history of sexual education for people with intellectual disabilities internationally has been characterized by neglect, distortion, and tolerance (33). Even today, there are perceptions that consider the sexual education of the disabled useless or dangerous and that it can lead this population to intense sexual activity. On the contrary, relevant research showed that valid information had a positive effect on the development of individuals' personality as a whole and on the adoption of responsible behaviors in sexuality issues (34).

In addition, the education on sexual matters was required to enhance the sexual awareness of people with intellectual disabilities on issues such as the prevention of sexual abuse (35), the prevention of sexually transmitted diseases and HIV infection, or pregnancy, as well as to achieve an appropriate sexual behavior in social settings. Education could enable the development of a positive sexual identity (14).

After all, as Paschou very characteristically stated, «the integration processes that society defends and promotes, require a more organized and appropriate preparation of people with intellectual disabilities in areas such as sexuality, interpersonal relationships, or social skills». Society, therefore, shouldn't deny their right to sexuality on the one hand and should fight for their social, school, and professional integration on the other (35).

Adolescents with intellectual disabilities need to be informed about the possibility of pregnancy and contraception, as well as about sexually transmitted diseases and their symptoms. It is important they to learn and distinguish what is legal and what is illegal and those sexual acts take place in private and do not concern everyone. Finally, they need to know that, for any sexual activity, they must give their consent and if they do not want to, they must make it clear to their partner (30).

In recent decades, there has been a significant change in the provision of care services, resulting in the state's efforts to meet the needs of people with intellectual disabilities and to include these people in its services. It has now become clear that cognitive functionality alone is not a criterion for assessing the population. (36,37,38).

## **Conclusion**

The findings of the present study aimed to stimulate the scientific and social recognition and promotion of the phenomenon of silencing the sexual awakening of adolescents with intellectual disabilities, as well as the phenomenon of discrimination and exclusion and to allow people with intellectual disabilities to be understood and accepted by society. The concerns and needs of adolescents with intellectual disabilities on sexuality issues were not differentiated fundamentally from those of the general population (39). Today, the main goal of the policy for people with intellectual disabilities is these people to have a normal lifestyle, like the rest of their fellow citizens. However, despite progress and growing knowledge about the phenomenon of intellectual disability, there are still problems with issues of intersexuality and sexual education, while psychosexual concerns are elevated (40).

In conclusion, there is a need for research to acquire knowledge specifically about the expression of sexuality of these adolescents. The collection of research data will, also, contribute to a better understanding between stakeholders on issues of sexuality and reproduction and will provide the state and the public health services with all the necessary information to design relevant information policies and strategies.

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