Sexuality and Persons with Intellectual Disability

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Abstract

Intellectual Disabilitydenotes sub-average intellectual functioning, based on IQ, accompanied by behavioral and developmental disorders. The issue of sexuality is still an obstacle inrealizing oneself as a whole person, of course in accordance with personal psychophysical abilities. The greatest problem is present in persons with intellectual disability, considered not apt enough for information on sexuality and for expressing themselves as persons with their own sexual needs. Sex education should contain information regarding biological, socio-cultural and spiritual dimensions of sexuality, including cognitive, affective and behavioural domains. Unfortunately, very few educational programs with such aims provide sex education, for the persons with intellectual disability population. Exclusion of sex education as a part of the educational cycle for this group means discrimination and depreciation of their essential human rights.

This article is based on investigations and its aim is to focus the attention of both professionals and non-professionals on this delicate problem.

KEYWORDS: Intellectual disability, sex education

Individuals with disabilities may be perceived as being asexual or hyper-sexual (i.e. sexually inappropriate). The stereotyping of individuals with disabilities as non-sexual or hyper-sexual beings has exaggerated misconceptions about the impact of an individuals' disability on his or her sexual functioning. Only recently, has information on sexuality, intimacy, and sexual functioning become part of the rehabilitation process of individuals with disabilities (i.e. spinal cord jury, traumatic brain injury, developmental disabilities, amputation, etc.)

Sexuality is a key part of human nature. People with intellectual disability experience the same range of sexual thoughts, attitudes, feelings, desires, fantasies and activities as anyone else. To understand and enjoy sexuality, everyone needs adequate information and support from a young age.Sexuality has psychological, biological and social aspects, and is influenced by individual values and attitudes. A person's sexuality develops throughout childhood and adolescence, and is a key part of their identity. The way each person understands and interprets their sexuality varies significantly, and often changes over time. Healthy self-esteem and respect for self and others are important factors in developing positive sexuality.

Most people with intellectual disability can have rewarding personal relationships. However, some may need additional support to develop relationships, explore and express their sexuality, and access sexual health information and services.

Our attitudes towards an understanding of persons with intellectual disability are changing and improving as knowledge and research in this field accumulate and more facilities become available to help us cope with this particular problem. A human being with a disabilities is first a person whatever his disabilities, he grows, eats, sleeps, behaves like his fellow man. Whatever his individual disabilities, he needs affection, friends, recreation, work, approval, success-just like the rest of us. The difference in a child with intellectual disability is that his development is slower and that he may not be able to speak or reason or understand quickly. His training requires much more patience, more knowledge and skill, continuous co-operation between trained professionals and parents.

.If you consider individual with intellectual disability firstly, as a human being and secondly, as a person with a handicap-if you think this person has a right to as good a quality of life as possible, then you must face the fact that his sexuality and sense of self, needs to develop and that should be treated with consideration and dignity. A child with intellectual disability will grow up and will develop physically. He will meet people of the opposite sex. He will be trained to use public transportation. He will sometimes be alone-not under the supervision of his guardian. He will go to work. He will have to look after his personal appearance and cleanliness. To do all this he needs to be as independent as possible.A good quality of life means acceptance by family members and social peers, vocational and recreational opportunities. If we recognize that a handicapped person is entitled to a good quality of life, we must take the responsibility of teaching him how to behave acceptably. He may not always be able to speak or reason or think or change his behavior pattern quickly, to suit a new situation, he must be trained from early childhood to act in a safe, healthy and acceptable manner towards other people and himself. It is our responsibility to understand his development and his needs, including sexuality, in order to guide and train him to cope with them.

The majority of people do not ponder upon their health, usually they do this only when it is lost. Health is the cluster of circumstances: life expectations, functional status, mental welfare, social wellbeing, quality of life. Mental welfare is an important dimension of health. Basic components of mental health are cognitive and emotional functioning (Schwartz 2008).

Sexuality and sexual health are important interconnected concepts. Sexuality encompasses a variety of physical, emotional, and social interactions and includes sexual beliefs, attitudes, knowledge, values, and behaviour (Travers &Tincani, 2010). Sexual health, on the other hand, is a state of physical, emotional, mental, and social well-being in relation to sexuality. It is not just the absence of disease, dysfunction, or infirmity. It requires a positive and respectful approach to sexuality and sexual relationships and the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence (WHO, 2015a, p. 1).

Regardless of the fact that individuals with intellectual disability have a problem in recognizing, expressing and balancing their emotions, they need:

- to have privacy
- to love and be loved
- to develop friendships and emotional relationships
- to learn about sex, sexual intercourse, safe sex and
- other issues related to sexuality (to protect themselves from sexual abuse)
- to implement their rights and responsibilities
- regarding privacy and sexual expression
- to enter marriage and become parents
- to develop personal sexual identity in accordance with age, social development, cultural values and social responsibility (Dorsey et al. 1998, Walsh et al.2000).

It is known that the issue of sexuality is very important, particularly to young people. Healthy young person very often mutually exchange information on this topic and get educated in this way, as well as through the media and family.
In special or inclusive school programs there is usually no talk about sexuality, although they are also individuals with sexual needs. Adolescents with intellectual disability experience through puberty the same hormonal storms as their healthy peers. Their parents are daily confronted with numerous problems and thus simply do not have either time or strength to introduce conversation on the topic of sexuality. Exclusion of sex education as a part of the educational cycle for this group means discrimination and depreciation of their essential human rights.

It must be mentioned that due to all these facts such persons are more prone to sexual abuse than the non-retarded, while unwanted pregnancies and sexually transmitted diseases are very frequent (Walsh et al 2000, Gust et al. 2003, Murphy & Elias 2006,)

Like their non-disabled peers, adolescents with intellectual disabilities participate in sexual activities. However, without appropriate information and education, they are unable to do so in a manner that promotes their sexual health. A lack of effective sexual health education can negatively impact individuals with intellectual disabilities in adolescence and throughout adulthood. More specifically, a lack of such education may lead to a higher risk of negative sexual health outcomes (e.g., sexually transmitted infections [STIs] and unplanned pregnancies), higher risk of abuse, and a lack of knowledge about healthy relationships.

Sexual knowledge among those with intellectual disabilities is generally lower than those in the general population (Dukes & McGuire, 2009; Galea, Butler, Iacono, & Leighton, 2004; Isler, Tas, Beytut, Swango-Wilson, 2011). This lack of sexual knowledge can lead to increased sexual risk-taking behaviours (e.g., not using contraception) and negative sexual outcomes such as unplanned pregnancies or the contraction of STIs.

Sexuality education for people with intellectual disability

A child's sexuality education comes from a range of sources, including their parents, teachers and friends.

People with intellectual disability also require sexuality education that:

- teaches them that people with disability can have fulfilling sex lives
- covers age-appropriate sexual issues that may be associated with their particular disability
- explains social rules, such as telling the difference between private and public behaviours
- is delivered in a way that a person with intellectual disability can understand.

It is important for parents to have access to the information they need to support their child in dealing with particular challenges they may face.

Some adults with intellectual disability may have received adequate sexuality education at school, while others may have missed out. Those who have received adequate education may need follow-up information that is suitable for an adult of their level of ability and literacy. For those who have missed out, it is important to start at the beginning, no matter how old they are.

Social opportunities, sexual relationships and intellectual disability

The opportunity to mix with other people of both sexes, whether socially, at school or at work, is important in developing confidence and social skills. However, some people with intellectual disability may have fewer opportunities to form social and sexual relationships for a number of reasons, including:

- a lack of privacy
- being dependent on others for daily living
- a lack of confidence about their physical appearance and ability
- less knowledge of how to negotiate relationships and express their sexuality
- a limited social circle and a lack of social experience
- physical or cognitive limitations
- carers who wrongly think of them as childlike or asexual
- carers who view their sexuality as something to be feared and controlled.

A person with intellectual disability may need additional support to explore sexuality and relationships. This can be particularly relevant to people with high support needs, for example, those who live with their parents or in supported housing, or those who need help with communication or personal care, such as toileting.

People in these situations may want sexual relationships, but wrongly, this may not be permitted by their parents or carers. They may lack the privacy needed for sexual activity. Restrictions at home may lead some people into unsafe or illegal activity, such as sex in parks or other public places.

Body image, intellectual disability and sexuality

In some ways, society presents a narrow view of how men and women should look, particularly through the media. A person with intellectual disability may feel less worthy of a healthy sexual relationship because they do not match this idealised image. Talking with other people who have overcome body image concerns or a counsellor may help.

Appropriate sexual behavior and intellectual disability

Sometimes, a person with intellectual disability may exhibit inappropriate sexual behaviour, such as public masturbation, or soliciting sex from minors or in public. This is more likely to occur when the person lacks more appropriate sexual outlets, or has not been provided with appropriate education about the complicated social etiquette and legal issues around sexual behaviour and relationships.

Sometimes, police may charge the person with a sexual offence. The person may also be restricted in unreasonable ways, such as a man being prescribed medication by a doctor to suppress androgens (male hormones). However, appropriate education and behavioural training are, in most cases, better ways of addressing issues such as these.

Unfortunately, some people with intellectual disability may have received the message that any sexual expression is unacceptable. This may need to be addressed before the person can learn more acceptable behaviours.

Sexual abuse or exploitation of people with intellectual disability

All people, including those with intellectual disability, have the right to enjoy relationships and sexuality without being abused or exploited. Unfortunately, statistics show that people with disability experience all forms of abuse at much higher rates than people without disability.

Reasons for this include:

- Inadequate sexuality education on where and when it is acceptable to be touched by other people
- Inability to resist, protest against or stop abusive behaviour from happening
- Not knowing that a person has the right to decide what happens to their body, especially if they are used to other people constantly attending to their physical needs.
- Being raised in situations where they are used to being told what to do and therefore going along with requests or demands made by an abuser.
- Agreeing to engage in sexual activity to fulfil unsatisfied cravings for attention, affection or rewards .
- Consenting to initial sexual activity, but not to sexual activity that follows, which amounts to abuse.

Just as in the wider population, assaults against people with disability are more likely to be perpetrated by somebody they know, such as a family member, carer, work colleague

or someone they live with. Research also shows that sexual assaults on people with disability are less likely to be reported.

Reasons for this include:

- Some people with disability find it difficult to communicate with others.
- A person may tell someone of the assault, but that person may not understand them.
- A person may have limited knowledge or ability to report what happened to them.
- Some people wrongly think the effect of sexual assault on a person with disability is not as serious as an assault on someone without disability.
- A person may not be believed.

Any sexual assault is a very serious matter and should be referred to police and sexual assault support agencies.

The carers of a person with intellectual disability can help by modelling assertive behaviour, making referrals if the person needs further training or support, and explaining the basics of protective behaviours, including:

- Every person has the right to say what happens to their body.
- Everyone has the right to feel safe.
- There are laws that protect a person's right to live safely without being harmed or exploited.
- There are many people who can be trusted, but also some who cannot be trusted.
- Some types of behaviour are appropriate for yourself and others, but some types are not.
- You can communicate assertively and say 'no' to unwanted behaviour.
- It is okay to change your mind about sexual behaviour or activity, even if you have already agreed to something.
- There are people who can help if you are being abused or exploited in any way.

Element of effective sex education

For sex education to be successful everyone involved must be comfortable: clients ,parents and professionals (Wallis 1991)Sex education programme must address the more than the physical aspects of sexuality. Such programme should focus on developing interpersonal relationship more generally, finding opportunities tosocialize, the responsibility that one has for one's body, the right and the ability to say "NO" and information about sexually transmitted diseases .In addition, programmes need to address the specific needs of the individuals rather than a generic curriculum. Such programme must be practical and based upon individual assessment.

Several other practical strategies have been identified that may be useful for educating individuals with intellectual disabilities about sexual health. These strategies can be used by parents and other caregivers, health professionals, and

educators. The strategies include (Egemo-Helm et al., 2007; Society of Obstetricians and Gynecologists, 2015):

- repetition of material
- being concrete (e.g., using pictures, videos, real-life examples)
- going through information slowly to ensure that the individuals can process the information, ask questions, and have discussions
- practicing the material through role-play, modelling, and rehearsal
- starting with basic information and moving to more complex issues
- teaching refusal skills
- practicing appropriate affection
- discussing masturbation (i.e., what it is, when it is and is not appropriate)

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