

# The S Words: Sexuality, Sensuality, Sexual Expression and People with Intellectual Disability

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**Abstract** The history of sexual suppression of people with intellectual disability is extensive and derives from primal fear of difference. The human rights imperative requires appropriate responses from services to support the sexual expression of people with intellectual disability. Ideas about how to support people with intellectual disability are provided.

**Keywords** Sexuality · Sexual expression · Intellectual disability · Learning disability · Australia

In relationship with others, I have learnt that sexuality touches the deepest essence of ourselves. How well do we foster that humanness, and how much does society deny that full humanness to those of us who are different? [1].

## Sexual, Sensual

Sensuality is awareness of one's senses (touch, taste, smell, hearing, seeing, thinking) and taking pleasure in those senses. Sexuality is an important part of the personality of every human being, is a basic need and aspect of being human, cannot be separated from other aspects of life, includes the physical, physiological, psychological, social, emotional, cultural and ethical dimensions of sex and gender, influences thought, feelings, actions and interactions and affects our mental and physical health. Sexual expression is choosing to or choosing not to be sexually active and need not necessarily involve another person (self-pleasuring).

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## Historical Responses to Sexuality

We wrongly assume that in this new century (the 2000s), societies around the world have advanced significantly since the societies of the 1800s. Whilst there have been quantum leaps in technology and science, we have come less far in attitudes towards people with intellectual disability and sexual expression. Historically, people with disability have been subject to sexual segregation, sexual confinement, marital prohibition and legally-sanctioned sterilisation under the guise of patient protection from pregnancy and sexual abuse [2, 3]. There are many misconceptions and fallacies surrounding the sexuality of people with disability. They may be regarded as asexual, i.e. they do not/should not have sexual needs and feelings. Hyper-sexuality (particularly used to describe sexual behavior of men with disability) or an excess of sexual desire is the other extreme of this negative attitude [2, 4–10]. Underlying the myths and misconceptions about the sexuality of people with intellectual disability form the basis of the eugenics movement [11] which to some extent continues to this day [12].

Today, despite advances, being a person with intellectual disability can mean lack of privacy, lack of control, lack of education, limited economic independence, being tested on deficits not strengths, being “other”, being a “captive of care”, having to be “grateful” and compliant, being at higher risk of abuse, and having no means of communicating [13].

Social barriers for people with disability are not simply the lack of ramps but complex systems and social attitudes [14]. People with intellectual disability are generally poor, have low levels of education, and generally enter their adult lives with little or nothing to do and few qualifications. Their social networks are limited and they have few friends [15].

## S is for Service

Sexual expression is not a problem for people with cognitive disability—but for those who work with them [16].

Although sexuality is an integral part of all of our lives, people with intellectual disability may find sexual expression inaccessible because of service barriers including institutionalised living, lack of privacy, lack of knowledge about what sexuality is and opportunities to express themselves [17]. Service responses to sexual behaviors in men with intellectual disability have ranged from the instigation of aversion therapies such as lemon juice on the penis to chemical or surgical suppression of sexual drive [6, 18]. Care providers can block people with intellectual disability access to sex education and can unwittingly give sexual misinformation [10]. There is a general fear that if we open the door to talking about sexuality, then people with intellectual disability will be abused or become sex offenders [19]. Even with people with autism, we make false assumptions that they will not be able to connect with others in deep and profound relationships [20].

By denying individuals with intellectual disability the opportunity to learn about their sexuality and develop social relationships with others, society has denied them the right to self-fulfilment. [10].

Swango-Wilson [10] undertook a descriptive survey of 85 people from the general population from 18 to 59 years of age in the USA, using Perception of Sexuality Scale (POS) and a demographic questionnaire, about their attitudes on sexual expression by people with intellectual disability, and found less support of same sex couples, anal sex and

prolonged public kissing. Safe sex programs, opposite sex partners, private and public shows of affection were considered appropriate for people with intellectual disability [10]. An attitudinal questionnaire about sexual expression for people with learning disability in Greece found that the majority of college-educated respondents considered sexual expression by people with learning disability to be healthy [21]. In interviews with staff from a medium-secure hospital in the UK where people with learning disability lived showed liberal attitudes towards masturbation and heterosexual feelings in the patients but staff did not approve of sexual intercourse and adults with intellectual disability making their own decisions about sexual expression [22]. A study of the attitudes of 261 adults from the general Australian community [17] found that general attitudes to people with intellectual disability expressing their sexuality were positive. A review of nineteen studies about support staff attitudes to the sexual behaviors of people with intellectual disability and mental illness found that sexual intercourse was not acceptable [23]. Restrictions within residences by staff and service policies specifically disallow homosexual activities although 33% men referred for sex education identify as being homosexual [5]. Legal consent issues restrict a person's sexual expression and provide an excuse to dismiss people who are able to give informed consent to sexual interaction [5].

### **Voicelessness**

Many people with intellectual disability do not have a viable means of communication [24]. Without a means of communication, it is very difficult to convey your needs and desires, and this leads to alienation and exclusion.

When I look back, I'm in awe of my achievements. How could someone go from living day to day in pre-arranged segregated activities in respite day centres to living in his own home with a real paid job and presenting far and wide? By dreaming and maintaining a strong will to persist. It was also vital to be able to communicate without relying on others to interpret for me. Really need to explore people who don't talk finding what works as an effective system of communication. It is a human right and as such must find ways to help others find their voice. I'm powerless without my voice. (Rod Mills, personal communication).

Before developing programs and services for people with intellectual disability, it is essential for service providers of any kind to support the discovery of communication channels for people with intellectual disability to express themselves [25].

### **Friends**

Poor life experiences lead to limited knowledge of the body, sexuality and sexual expression. Prohibitive environments wherein care providers maintain the belief that people with intellectual disability are eternal children restrict a person's access to social opportunities [26]. The lack of relationships affects all aspects of a person's life and people with intellectual disability are no exception.

A comparative study by McCabe [8] of the sexual knowledge and attitudes of 60 people with intellectual disability, 60 people with disability, and 100 people from the general population found that people with intellectual disability know less about sex and have negative attitudes as well. Homosexuality was noted at the same rate as the general

population. Masturbation was higher and exposure to sexual activity with another person was lower. Respondents with intellectual disability wanted to experience dating, intimacy and sexual interaction but felt timid because of their lack of knowledge, their negative feelings and their lack of opportunity.

As with the general population, adults with intellectual disability want to know how to meet people, how to talk with people they were interested in, and how to invite someone out [27], regardless of the organisation of residential living which prevents intimacy developing [28].

A mother's story about her adolescent son with Down syndrome and how he wanted to find a girlfriend illustrates how we unconsciously exempt people with disability from forming relationships with non-disabled people. In the story, the mother and son were watching people pass by and she pointed out a young woman with Down syndrome and her son reacted negatively saying no, he didn't want her and that he needed a girlfriend who had her own car and licence [29].

Fostering opportunities to explore everyday relationships is a challenge and often pushes people to their limits but the right to take risks is accepted in the general population and yet not in people with intellectual disability [20].

## Impairment and Illness

Illness and impairment impact on sexual expression.

Wiwanitkit [30] studied the effect of Parkinson's disease on sexual expression. Women reported difficulties with arousal, orgasm and low sexual desire; and men reported erectile dysfunction; sexual dissatisfaction and premature ejaculation. Physiological problems in Parkinson's like speech and postural instability causes problems in sexual function, and the concomitant depression is also reported as a common reason. The use of antidepressant medication makes it worse [30].

The physiological impact of chronic illness or impairment on sexual expressivity cannot be underestimated. For example, People with multiple sclerosis report sexual dysfunction because of pain, numbness, fatigue, coordination problems, and body self-image [32]. People with spinal cord injury or dysfunction report similar problems with orgasm and arousal principally because of coordination problems and self-image [33]. On the other hand, sexual expression to orgasm can alleviate pain, as in the example of a study of 63 women with fibromyalgia in Europe [31], where sexual intercourse actually gave relief and a distraction from the continuous pain. Despite the benefits of orgasm, the women still considered that their level of intimacy in relationships was far more important than the sexual acts.

In one study in the USA of 410 individuals with serious mental illness who reported sexual activity, who had been living in both state institutions and community housing for between 18 and 60 years, found significant problems with sexual isolation. Some of the reasons for sexual difficulties included poor access to sexual partners (39%), experiencing sexual dysfunction mainly due to effects medication (29%), history of abuse so reluctance to start relationships (23%), fearing disease or pregnancy (23%), moral or religious doubts (23%), and sexually restrictive treatment cultures (21%) [34].

Mental health issues often derive from traumatic life events including sexual abuse in childhood and can be circular in creating ongoing life problems [35].

Since people with intellectual have few friendships, life can be lonely and this suppresses self-esteem and ease of sexual expression [36].

## Drugs and Sex

Most neuroleptics and antipsychotics cause sexual dysfunction [30]. Most traditional neuroleptics produce adverse side effects including sexual dysfunction, weight gain, hypersexuality and aberrant sexual behaviors (drug induced psychosis). People with intellectual disability who have psychotic or behavioural disorders are at risk of developing movement disorders from extended use of antipsychotic agents [37].

## Environment and Boredom

The poverty of life experiences for many people with intellectual disability is profound [38]. Limited access to meaningful daily activity and/or employment reduces a singular life to eating and sleeping. Self-stimulation through masturbation may in fact be the only way to survive persistent boredom in restrictive environments [39]. People with intellectual disability may masturbate to calm, or to get feedback otherwise unobtainable in their lives [40]. However, scratching, touching, rubbing around genital areas may well be interpreted as masturbatory behavior rather than a health or comfort issue [16]. Restrictive environments discourage the use of pornography and other materials to support safe sexual expression and this can force people with intellectual disability into prostitution [5, 41].

## Hetero not Homo

Swango-Wilson [10] found that respondents in her study were less supportive of same sex couples. Homosexuality and bisexuality as sexual identities are considered either as anathema or part of a person's with intellectual disability development towards heterosexuality [42]. In interviews with staff from a medium-secure hospital in the UK, staff did not approve of homosexual relationships [22]. A study of the attitudes of 261 adults from the general Australian community [17] found that there were generally negative attitudes towards homosexuality in adults with intellectual disability. A review of nineteen studies about support staff attitudes to the sexual behaviors of people with intellectual disability and mental illness found that heterosexual rather than homosexual activity was accepted [23]. Restrictions within residences by staff and service policies specifically disallow homosexual activities although 33% men referred for sex education identify as being homosexual [5].

## Not Normal

Establishing and maintaining sexual and intimate relationships during an adult life is an expectation in most cultures [34], and yet, people with intellectual disability are sexually disenfranchised [43].

“People with disability are normally perceived as sexually undesirable or less desirable than non-disabled people. One of the reasons for this negative attitude towards sexuality of people with disability is the idea that they are considered physically unappealing and hence not in a position to attract a sexual partner. Such ideas lead to the person's perception of him/herself as ugly and sexually incompetent. The absence of positive role models of

people with disability creates further confusion in the minds of young people with disability giving the negative message about the possibility of sexual fulfillment” [11].

The Australian Study of Health and Relationships [44] found that 85.3% of men and 89.5% of women are in regular heterosexual relationships, that 1.6% of men identified as gay and 0.9% as bisexual. For women, 0.8% of women identified as gay and 1.4% as bisexual. However, 8.6% of men and 15.1% of women reported either feelings of attraction to the same sex or some sexual experience with the same sex. In the past year 65% of men and 35% of women had masturbated [45]. This Australian study is consistent with what little we know of people with intellectual disability and their sexualities [4, 5, 46–52].

## Having the Words

People with intellectual disability have the same rights as others to have “accurate information, comprehensive education about sexuality and sexual health services” [53]. Sexuality education improves self-esteem and gives people the right words.

Whilst society tolerates the abuse of people with intellectual disability [54], abuse may arise from their lack of sexual skills and being able to communicate the correct information about their bodies [55]. A comparative study of 60 young people with intellectual disability and 60 young people without intellectual disability [56] found that people with intellectual disability had significantly less knowledge than their counterparts without disability about pregnancy, masturbation, contraception, STDs, types of sexuality and the law. Additionally, they had less understanding of social situations and were more vulnerable.

Sexuality education helps people with intellectual disability to recognize inappropriate sexual advances and be able to report incidents of suspected sexual abuse, as well as teaching some of those essential skills in social etiquette and self-care [9]. Whilst being educated around body and self contributes to the reduction in vulnerability, it also reduces inappropriate sexual expression [10, 16].

Efforts are made to teach people with intellectual disabilities to feed, clothe and bathe themselves. Why then is it not possible to teach people to masturbate privately and safely? [16].

Educational programs for people with intellectual disability should be age appropriate, not centred on their cognitive impairment but focus on sexual expression as an ordinary part of an ordinary life [27, 57]. In the UK and Australia, the *Sexual and Relationship Facilitation Project for People with Disabilities* [28] supports people with disability to improve their body feelings and self-esteem. Involving both support staff and people with intellectual disability in the conversation about sexuality achieves a greater humanisation of services. Freedom of informed sexual expression can alleviate self-injury and ‘challenging behavior’ [58, 59].

## P is for Policy

Whether we like it or not, whether we approve it or not, whether we prohibit it or not, people with learning disabilities are having sex, and it is the service responsibility to ensure that they are safe.

One of the reasons work in sexuality is formalized through policies and guidelines is that sexuality is a difficult issue for service cultures. Whilst organizations might subscribe

to basic rights frameworks, prohibition of sexual expression by people with intellectual disability in their own homes is a contemporary phenomenon.

Whilst international law protects the rights of people with intellectual disability, national laws around capacity to consent often block those rights. Those laws whilst aiming to protect from abuse consequently disempower and remove rights. This is further complicated if support workers are assisting people with intellectual disability to access sexual relationships [60]. Clear policy development obviates this confusion.

Policy benefits are not immediate. Clear guidelines around sexuality and sexual expression of service users helps workers feel supported, identify the role of family and it helps people with intellectual disability feel respected. Policy can directly address difficult subjects such as social relationships with support staff, physical interaction, accessing sex shops, and how to support social opportunities in the person's home.

## H is for Humanity

According to the World Health Organization, sexuality is integral to being human [61].

Sexuality and sexual expression should be celebrated as a healthy part of being human [62].

As a person with intellectual disability matures, they will experience normal sexual desires and feelings. For some young people with intellectual disability, masturbation may be a way of expressing sexual feelings, and this can be considered a natural and healthy way of expressing sexuality [63]. Persistent masturbation may be an indication that the person is not actively involved in something that interests them [9].

## Concluding Statement

People with intellectual disability experience the same range of sexual needs and desires as other people. With appropriate education and good social support, people with intellectual disability are capable of safe, constructive sexual expression and healthy relationships. Providing such support is an essential part of supporting people with an intellectual disability [7].

People with intellectual disability have experienced a long history of sexual repression. Within the current context of rights, people with intellectual disability are entitled to live free sexual lives. In order to live sexual lives, people with intellectual disability need regular social lives so that they can make friends, education about sexuality and their own bodies, a means of communicating their sexual needs, opportunity for sexual expression and relationships, privacy, and the right to make mistakes. All of these are aspects of our own lives which we take for granted and removal of those rights would cause us consternation. A protection of a person's sexual rights must include service providers having policies to support the person's life planning around sexual expression. Supporting people with intellectual disability to live full lives means supporting them to live a full sexual life.

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