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**Original article**

## **Analysing the disability- sexuality controversy**

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### ABSTRACT

Sexuality is one of the many phenomena which are least openly discussed particularly in the African culture. Sexuality is conceived variously in different cultures and disability is seen as a threat to sexuality in many of the cultures. Meanwhile, sexuality is regarded as a central theme in the development of self-esteem and self-identity since it has been conceived within the bodily perfection and bodily beauty complexes. Thus, the way sexuality is conceived for people with disabilities forms the central thrust of this paper. Views about the sexuality of people with disabilities have manifested in the construction of what we term the disability- sexuality controversy. The paper examines this controversy and explores ways of resolving it in the context of educational programming. The paper concludes that the disability- sexuality controversy is more of a social than a biological construct. This conclusion is premised on the hypothetical view that both disability and sexuality are intimately tied to the concept of self in which case sexuality is constructed within the social realm of the bodily beauty complexes. The way forward is a multi-sectorial approach towards the eradication of disability stereotypes. In addition, the paper recommends active parental involvement in the programming and implementation of sexuality education for their children with disabilities.

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## **1. Introduction**

From a clinical point of view, disability is inability to perform an activity that other persons of the same age, sex and culture would ordinarily perform. It occurs as a result of a loss of a body part or function. A loss of a body part or function is called impairment. According to Barnes and Ward (2000), disability is any restriction or lack of activity resulting from an impairment to perform an activity in the manner or in the range considered normal for persons of the same age, sex and culture. From a sociological perspective, Silverberg (2009) sees disability as a 'social disease.' What this means is that, disability is socially constructed. Thus, for people with disabilities, while the impact of disability could be equally painful, what is more annoying is the negative attitudes of the non-disabled members of society and the systematic barriers society imposes on the lives of the disabled. Sexuality on the other hand, is defined by Jaffe (1998) as the set of properties of human creation and procreation which are influenced by evolution, genetics, nervous and hormonal systems, cultural mores and prohibitions, religions and ethnic traditions. It also involves interactional aspects of self gender, peers, family and societal influences. Thus, sexuality is not limited to reproductive and gender issues alone. It also involves sexual expressions, all developmental traits, roles, interpersonal responses, norms, values and belief systems. For Ratzka (1998), sexuality is a form of communication and a means of expressing one's own personality toward other people. In many cultures, sexuality is conceived as an intimate expression of self to the extent that it is not easy for one to openly discuss their sexuality with anybody. From this analysis, we can see that both disability and sexuality are complex social constructs. Their interaction creates a majestic complex conundrum which is not that easy to synthesise. Walker-Hirsch (2010), observes that both disability and sexuality are emotionally loaded constructs. Combining them is a recipe for disaster. What makes the interaction of disability and sexuality even more complex is that they are both intimately tied to the self-esteem and self-concept of the individual. However, Silverberg (2009) earlier on argued that, while it is often hard for people with disabilities to understand the relationship between disability and sexuality and while the relationship is not a simple one, the relationship is not always a negative one.

## **2. The Interaction of disability and sexuality**

Irwin (1997) rightly points out that, in general society; sex has been considered a taboo topic. In the same vein, disability has been seen as a subject of pity, shame or guilt. Goldberg (1984) notes that problems of sexuality are prominent among people with disabilities due to the controversial conceptions of both disability and sexuality in different societies. This suggests that disability can and does impact on one's sexuality in many ways. The impact of disability may not only be physical but can be psychological or social as well. The physical impact relates to limitations of sexual activity in terms of access and attractiveness to a sexual partner. It also relates to the way one engages in sex, that is, the ability to engage in those sexual activities that suit the type of disability within the limits of one's tolerance levels of physical activity. This is coupled with the physical responsiveness of the partner in terms of his/her ability to adjust to the relative needs and preferences. Ashcraft (2006) observes that, depending on the type and severity, disability can indeed affect sexuality. Furstenberg (2000) earlier on identified multiple sclerosis, spinal cord injuries and brain damage as some of the disabling conditions that have potential physical negative impact on sexuality. While Silverberg (2009) acknowledges that, a mobility physical disability can indeed impact on sexuality, he is of the opinion that this observation may only hold when people think of sex as involving a strong erection and a well lubricated vagina. Sex means more than just sexual intercourse. The author observes that even somebody with a spinal cord injury, who, as a result cannot achieve an erection still has a 'thousand' options to have sex and feel sexy for example. The biggest barriers in this respect are lack of options, opportunities and variety to experiment their sexuality, lack of creative methods of sexual activity, lack of problem solving skills and inaccessibility to an understanding partner.

Tied to the physical impact of disability on sexuality is the psychological impact. This is connected to the conception of sexuality as a self-concept and bodily beauty construct. How one feels about themselves can influence the way they feel about their sexuality and consequently their ability to find a sexual partner and to engage in gratifying sexual activity. The psychological impact of disability is also related to the onset of the disability. For instance, a person with an adventitious physical disability may take more time trying to psychologically adjust to the disability and in the process take a long time to readjust to his or her sexual identity. Adjusting to a disability is a complex and individualistic process. It involves, among other things, integrating the disability and subsequent assistive devices that go with the disability into one's identity and adjusting to a new

sexual life. For Silverberg (2009), while there are systematic social barriers in education, entitlements and rights, finances, employment, health care systems and housing that impact on people with disabilities in very similar ways, the sexual experiences of people with disabilities are varied and individual.

Although the trend is now different in many societies, extensive literature on disability concurs that people with disabilities are often shun away by society. People with disabilities are looked down upon and many cultures would frown upon a non-disabled person who develops a sexual relationship with a disabled person. There are so many myths, that is, mistaken conceptions about the sexuality of people with disabilities so to speak. Some of the myths that have partly resulted in the sexual alienation of people with disabilities are that people with disabilities are:

- Asexual
- Do not need sexual partners
- Homosexual
- Not sexually attractive

These are the myths that have also fuelled sexual abuse of people with disabilities. People with disabilities have been taken advantage of in many ways. They have been sexually abused and assaulted. As a result, their self-worthiness with respect to sexuality have been badly damaged. Surprisingly, in the public domain people with disabilities are said to be less sexually attractive but in practice they have suffered greater impact of sexual abuse. The National Disability Authority in its review of literature on the incidence of sexual abuse discovered that people with disabilities were 2.9 times likely to experience physical or sexual abuse. For Silverberg (2009) the statistics stand between 2 and 10 times more likely for people with disabilities to be sexually assaulted as compared to non-disabled people. A survey of women with physical and/or intellectual disabilities in the USA revealed that, 53% of them had experienced sexual abuse at some point in their lives (Powers; Curry; Oswald; Maley; Saxton and Eckels, 2002). From these and other more stunning statistics, it would appear that people without disabilities have used the survival of the fittest strategy against the disabled! In addition, people with disabilities are systematically denied the rights to education, employment and health services such as sexual health services etc. This has created a society of minors or outcasts who have no say in their sexuality, who cannot be on their own, who do not deserve privacy or to say the least, who have no business with sexual issues. Such practices have somewhat acted as if to justify the mistaken conceptions and myths about the sexuality of people with disabilities.

### **3. Cultural stereotypes about disability and sexuality**

Some societies view disability with cultural and religious connotations. For example, in some sections of African tradition, disability is believed to be a result of witchcraft. In some religious circles, it is seen as a punishment from God for a sin committed by the parents. In the same vein, sexuality is seen as a cultural construct. Priestly (2003:97) asserts that in some cultures, "Not only have disabled people been constructed as less attractive or desirable, their potential for expression of sexuality has been both denied and regulated". According to Taleporos and McCabe (2001), this is because powerful myths surrounding disabled people's sexuality have been reproduced through cultural taboos. These cultural taboos or stereotypes include portrayal of people with disabilities as asexual, sexually threatening or homo-sexual. In some instances, there are unfounded beliefs that having sexual intercourse with a female with intellectual disability for example can cure HIV and AIDS. Quite absurd, isn't it? Hughes (2000) however argues that, these stereotypes have been constructed on the basis of exclusively, the body beauty and the narrow limited views of disability.

From the foregoing analysis what really complicates the disability – sexuality controversy, is that sexuality is culturally normed on the bodily beauty complex. Within this complex conundrum, there are culturally imposed standards for beauty particularly for women. The standards are clandestinely premised on the false conception of a 'complete' and 'full' human being. These beliefs have unfortunately been seen as parameters for self worthiness. Bekman (1975) in Shrey, Kiefer and Anthony (1984) postulated that, there is a strong relationship between sexuality and self-identity or self-esteem. Stone (1995) concluded from Beckman's views that the myth of sexuality as a function of bodily perfection is a long standing factor which has always haunted disabled people and which has systematically complicated their sexual lives. For Talesporos and McCabe(2001), the perpetuation of the myths has also been largely due to the trans-generational ideal of sexuality which has a strong cultural link with the myth of bodily perfection. Imagine that for some people with disabilities, the assistive devices such as wheel-chairs and

hearing aids become part of the self. They become systematically excluded from the list of the 'complete' and the 'beautiful'.

#### **4. Discussion**

The foregoing analysis shows that, in the main, the impact of disability on sexuality is not related to the disability itself but to the society which is unreceptive to the needs of people living with disabilities. Silverberg (2009) insists that what makes the sex lives of people living with disabilities difficult has a lot more to do with society than with disability itself. Testimonials found in literature, of many people with disabilities suggest that people with disabilities are able to fully express themselves sexually. They also have the same aspirations of marrying, procreation and raising a family as their non-disabled peers (Ridell, Baron and Wilson, 2001). As such, Shakespeare (2000) is of the opinion that, in the absence of these restrictions, disabled people have the capacity to demonstrate and achieve complete sexual activity and expression. Disability activists and disability culture have begun to redefine aesthetic norms of sexuality in order to challenge the oppression of the aesthetic value of people with disabilities (Priestley, 2003). What the non-disabled community may see as beauty the disabled may not see it as such. Beauty is contextual and people with disabilities have their own unique experiences that are not necessarily at tandem with the majority view about sexuality.

For that matter, according to Morris (1999), the cultural controversy of sexuality and disability is more pronounced in African and Asiatic than in more industrialized cultures. In America, for example, the definition of generic terms such as gender has changed over years to include more dynamic aspects. This has resulted in new ways of conceiving sexuality. At the same rate, acceptance of people living with disabilities is increasing at a faster rate than ever. The net result of these changes has been an improved outlook of the sexuality of people living with disabilities in those industrialised societies. To this end, Trust (1990) confirmed that in most industrialized countries, although not necessarily seen as desirable, expression of sexuality by people with disabilities is seen as inevitable. However, this is not always true. Even in these industrialised countries, sexuality of people with disabilities is still marred in controversy because the people with disabilities themselves are still seen as 'people who need help they are a weak species'. For Atkinson, Smith and Hilgard (1987), technological changes relating to sexuality, even in industrialized countries have produced more controversy yet the controversy can be resolved through deliberate educational and community awareness and intervention programmes.

It has become clear that the disability–sexuality controversy is more of a social than a biological construction. It would appear that, persons with disabilities need more of societal support for them to express their sexuality in positive ways. The beliefs that people with disabilities are not sexually active are not convincing and lack empirical bases. These beliefs are only cultural opinions premised on stereotypes about disability and sexuality. However, Freiberg (2002) and Ashcraft (2006)'s analyses about the likely physical impact on sexuality cannot be overlooked and society cannot afford to ignore the obvious negative biological impact that particular physical disabilities might have on one's sexuality. But, this should only be viewed within a genuine framework of assisting people with disabilities overcome challenges relating to their sexuality. The level of impact of disability on sexuality would largely depend on the severity and type of disability. It would also depend on the disabled person's self-awareness, assertiveness and creative ability with respect to what constitutes sex. The lower the person's self-esteem the more the impact of disability on sexuality. The level of societal acceptance is also a key factor in determining the integrity of one's sexuality.

#### **5. Conclusion**

This paper therefore concludes that, the fact that both disability and sexuality are socially constructed means that the relationship between the two is also only existent in non-disabled people's minds. The paper also infers that with adequate support, the sexuality problems of people with disabilities can be drastically reduced. The support can only be meaningful owing to demystification of the disability-sexuality controversy. This can be effectively achieved if society comes to its senses and acknowledge that, first and foremost, people with disabilities are 'complete' human beings like anyone else. They have abilities, aspirations, feelings and ideas. In the ultimate analysis, the disability-sexuality controversy is dynamic and complex and forms a vicious cycle which may not be easy to break because of its deep-rootedness in the long standing cultural versus biological discourses.

One strategy of reaching to the community and ultimately breaking the cycle of the sexuality-disability controversy is undertaking sexual awareness programmes such as community sexuality awareness campaigns, sexuality education and sexual adjustment counselling programmes for the persons with disabilities and their families and communities. Parental involvement is critical in these regards. Regrettably, in a study, by Anderson, Clarke and Spain (1982), many parents reported that they were particularly not well informed about the sexual development of their disabled children. Sitlington (1996) justified sexuality education and sexual adjustment counselling for disabled adolescents on the basis that they can mitigate the impact of HIV and Aids as well as the breakdown of the extended family system. Sexuality education can also improve the sexual image of people with disabilities. This can further boost their confidence when it comes to seeking suitable partners and achieving gratifying sexual relationships. Sailor and Guess (1983) implored that, it is important that sex education and counselling are included in a combined school-home programme in order to break the controversy between disability and sexuality. Sex education involves teaching of the reproductive process and reproductive health, skills for prevention of sexually transmitted infections including HIV and AIDS, prevention of unplanned/unwanted pregnancies, sexual priorities and values, roles and preferences as well as the significance and implications of the cultural and religious belief systems (Fursterberg, 2000). Since we have seen that people with disabilities are vulnerable to sexual abuse, the issue of protection should feature prominently in sexuality education. Jaffe (1998) earlier on observed that, many school systems and parental groups have waged legal battles over what should constitute a sex education curriculum. Perhaps that is why a multi-disciplinary approach is necessary straight from programming through to implementation. The sexuality-education and sexual adjustment-counselling programmes should be a collaborative effort involving the school, the community, other professionals and persons with disabilities and their families.

For sexual adjustment counselling, the goal is to help the individuals with disabilities feel more positive about their sexuality (Ammerman, Van Hasselt and Hersen, 1987). Shrey et al (1984) defined sexual adjustment counselling as those skilled activities of the rehabilitation professionals which facilitate the disabled person's positive outlook of his / her sexuality. For sexual adjustment counselling to succeed, UNESCO (2008) advises that professionals should be knowledgeable and should not ignore the power laden gender dynamics. It follows that, within the sexuality-education and sexual-adjustment counselling paradigms, assertiveness training should be provided especially to adolescents with disabilities but not before professionals are adequately inducted in handling these programmes. One problem is that available materials and resources were designed with non-disabled in mind. The other problem is of accessibility of the materials and resources to people living with disabilities. Modification and adaptation of materials and resources and improved information dissemination would be required to ensure that people with disabilities benefit from these programmes. Irwin (1993) notes that while generic sex education materials may be appropriate for most people with disabilities, adaptations may be needed for others.

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