

Disability, the Stigma of Asexuality and Sexual Health: A Sexual Rights Perspective
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Abstract: This article discusses the stigma of asexuality generally attributed to persons with disabilities. It examines how this stigma poses a barrier to attainment of sexual health. It argues that health programming must treat persons with disabilities as sexual subjects who have sexual rights in order to advance their sexual health.

Key Words: disability, stigma of asexuality, sexual rights

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HIV/AIDS is one of the challenges that persons with disabilities face today. There have been calls to include persons with disabilities as sexual subjects in HIV/AIDS programming. However, while such programs may indeed include persons with disabilities, the stigma that persons with disabilities are asexual can hinder efforts to adequately address their sexual health needs, including HIV/AIDS. The stigma operates to exclude persons with disabilities from being treated as sexual subjects having sexual rights.

The aim of this article is to explore the challenge posed by the stigma of asexuality in the context of sexual health, and to argue for the recognition of persons with disabilities as full sexual subjects. This is crucial because sexual health and HIV/AIDS prevention programs that do not also address the stigma of sexuality will fail to fully address the sexual health needs of persons with disabilities and may continue to marginalize them.

Constructing Disability

Before embarking on the discussion of sexual health as it relates to disability, the concept of disability itself shall be examined, as it is understood from various perspectives. Several models of understanding disabilities are discussed under the individual pathology and social pathology paradigms (National Human Rights Commission [India], 2005).

The Individual Pathology Paradigm

The charity model constructs persons with disabilities as unfortunate victims of nature gone awry and therefore deserving society's pity and charity. The location of the problem is in the individual, who by virtue of some physiological or psychological characteristic is labeled handicapped. Some say "handicap" literally derives from the image of a beggar with a "cap" in "hand." Policies on disabilities influenced by this mentality emphasize welfare and charity.

The medical model also focuses on individual pathology. The emergence of the medical model is associated with the rise of scientific thinking in the Enlightenment Period (Udwadia, 2000). The medical model is based on a positivist philosophy with its attendant assumptions about the nature of the social world and methods of investigating it. These assumptions consist of the belief that the world could be studied in the same way as the natural world, and that there is a unity of method between the study of the natural and social sciences (Rioux, 1994a).

The medical model conceives disability as impairment of an individual, and focuses on disability as an abnormality subsisting in the individual. A person with a disability is therefore measured against a certain standard of normalcy. He or she has a disability in so far as he or she has deviated from normalcy (Shakespeare, 1996).

The medical model with its scientific and positivist philosophical basis has a powerful influence on society. Smart & Smart (2006) say that the biomedical model carries the power and prestige of the medical profession that commands the respect of society. This is why disability seen through the medical perspective gained a strong foothold in many societies.

Locating disability in the person and conceiving disability as an objective condition subsisting in the person, also justified discriminatory treatment (Rioux, 1994b). What if a disability could not be “eliminated?” Inevitably, elimination of disability conflated with exclusion or elimination of persons having disabilities. This was done by institutionalization, segregation of schools, asylums and sheltered workshops.

The stigma and discrimination against persons with disabilities was also encouraged by the development of the science of eugenics. This was to have one of the harshest effects on persons with disabilities, because they were thought to be reservoirs of undesirable genes. Rioux (1994b) has noted as follows:

“The enthusiasm of the eugenicist and psychometricians for finding a scale to measure innate difference was translated into scientific evidence of inferiority and superiority. In the hands of governments and lawmakers, the scale became a means to differentiate and justify unequal treatment, including the restriction of basic citizenship rights such as procreation, marriage, immigration, education, property ownership and ability to contract” (p. 72).

The stigma surrounding the sexuality of persons with disabilities was therefore legitimized by science. Denying their sexuality or imputing a perverted sexuality are two sides of the same coin; justifying the social and legal control of their access to sexual activity and expression, and most importantly, procreation. One way of perpetrating this was through involuntary sterilization. This mentality is reflected in the case of *Buck v. Bell* (1927) where Justice Oliver Wendell Holmes of the United States Supreme Court made the following statement in favor of the sterilization of a person with a mental disability:

“It is better for all the world if instead of waiting to execute degenerate offspring for crime, or to let them starve for imbecility, society can prevent those who are manifestly unfit from continuing their kind ... three generations of imbeciles are enough” (at 207).

The Social Pathology Paradigm

What has been called the functional or rehabilitation model is discussed here as an extension of the medical model, but at the same time as a precursor to the social model. In part as a result of further advances in medicine, and in part because of the need to reintegrate into a more or less normal life those citizens who had acquired disabilities because of two world wars (Kaplan, n.d.), there was the beginning of a shift from the individual pathology paradigm to the social pathology paradigm. The functional model perceives the person as needing assistance through services and supports aimed at making the individual as functional as possible (National Human Rights Commission [India], 2005).

This understanding of disability brought about the era of rehabilitation programs. This included services such as physiotherapy and occupational therapy, and skills training. Medical technology was harnessed in research to manufacture assistive devices, for the purposes of assisting the person with a disability to lead a normal or closer-to-normal life.

The advent of the rehabilitation era reflects a mind-shift from treating persons with disabilities as deserving charity or cure and justifying subtraction of rights, to regarding them as persons who were entitled to rights, and needed assistance to negotiate diverse environments.

The rehabilitation model paved the way for people with disabilities to question the authority of the medical model. The paradigm shift was complete when disability was conceptualized as the barriers society imposes on persons with disabilities. This has been referred to generally as the social constructionist model. According to Jones and Basser Marks (1998) “...the social constructionist approach to disability tries to uncover the subtle societal factors which interplay with personal experiences which and together create, reinforce and potentially perpetuate the subordination of persons with disabilities” (p. 3).

The social model therefore arose primarily as a critique of positive science, which posed as the dominant discourse. The social model of disability was a reaction to the conceptualization of disability by the biomedical sciences, which considered disability as an objective phenomenon in the individual (Diedrich, 2005).

The period following World War II saw the inception of the modern human rights movement. This spurred civil rights movements, including the disability movement, to frame their concerns in terms of human rights. Disability movements conceived advancement of their human rights concerns as an emancipatory and political project.

They insisted on entitlement to full citizenship rights (Cole, 2007). They criticized the policies and laws that were based on the medical model, which perpetuated negative stereotypes, and justified the exclusion of persons with disabilities from the benefits of citizenship (Prince, 2004). Removing social barriers and achieving equality was central to the project:

“Without a concept of social barriers to full participation in society, a movement from the welfare approach to a rights-based legal paradigm would not have been possible. People with disabilities could not be conceived as equals while there was an automatic assumption of inferiority and incompetence” (Jones & Bassar Marks, 1998, p. 6).

The social model is not without criticisms (Terzi, 2004). It is not within the scope of this essay to examine these. Suffice to say that the medical model and the social model have contributed to the conceptualization of disability and continue to be influential in social policy and law (Ngwena, 2006). Therefore, an integrated approach that combines both models greatly enhances the potential to empower persons with disabilities. Most importantly, it also allows disability to be a subject of human rights. Persons with disabilities are therefore subjects of human rights including sexual rights. Disability does not subtract any human rights from any human being.

Sexual Rights and Related Concepts

The thinking about sexuality in the context of rights, and eventually evolving into the framework of sexual rights, has gained visibility on international political agendas only recently. The subject of sexual rights therefore is still evolving.

The concept of sexual rights is explored here, and the related concepts of sexuality and sexual health, which are pertinent to the discussion of sexual rights as it relates to persons with disabilities. The World Health Organization (WHO) has through consultation with experts come up with definitions of these concepts, and they shall be adopted in this work. The advantage of adopting these definitions, though not official WHO positions, is that they come from an authoritative world-body and enjoy wide political legitimacy. However, this is not to gloss over the fact that these concepts may not enjoy unanimous acceptance.

Sexuality and Sexual Health

The difficulty of coming up with one universally acceptable concept of sexual rights arises from the fact that sexuality itself, which is the subject of sexual rights, is a term imbued with many meanings (Weeks, 1986). To begin deconstructing the term, the different philosophical underpinnings of its conceptualization need unraveling. Two main perspectives have shaped the understanding of sexuality: essentialism and social constructionism.

Essentialism implies the belief that certain phenomena are natural, inevitable, and biologically determined (DeLameter & Hyde, 1998). From this perspective, sex and sexuality are intricately linked to reproduction, and women's sexuality to motherhood. One consequence of such conceptualization is the institutionalization of heterosexuality, where family and marriage are the privileged sites of sexual intercourse and child rearing (Carabine, 2004).

From the social constructionist perspective, sexuality is not a biological given but is socially and culturally constructed (DeLameter & Hyde, 1998). Sexuality therefore is a social construct whose meaning is derived from language or discourse; a way of thinking and talking about behaviors that are considered sexual or not sexual (DeLameter & Hyde, 1998). Carabine (2004) says that the social constructionist perspective places emphasis on the social meanings that an individual attaches to specific sexual acts, behaviors, feelings, desires and relationships.

Another feature of sexuality is that it is experienced at the individual and personal levels as well as at the social level. Carabine (2004) says that:

“At a personal level, sex and sexuality may invoke different sets of ideas and feelings in us to do with intimacy, privacy, pleasure, excitement, desire, embarrassment, attraction, age, fear, pain, abuse, control, freedom, fulfillment, danger, constraint, disease, well-being, our bodies, love and emotion” (p. 2).

At the sociocultural level, sexuality is constructed to serve a variety of needs: sex is a means of procreation, an intimate bonding ritual, even a form of social control (Rye & Meaney, 2007). It is this characteristic of being private and at the same time public, arising as a biological given and at the same time socially constructed, that sexuality is a highly contested and contradictory terrain. Its malleability and capacity to evoke varied interpretations invokes fierce political and public debate (Carabine, 2004).

Ultimately, a useful definition would try to capture these aspects of sexuality. The working definition by WHO (2004) International Technical Consultation on Sexual Health affirms the complexity of the term:

“Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. . . . Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.”

From this discussion and definition, it is appreciated that sexuality is a central aspect of being human and is experienced in diverse ways. The experience of sexuality is also dependent upon the interplay of various biological and social factors.

The definition of sexual health logically flows from the definition of sexuality. The definition of sexual health by WHO (2004) is one of the most influential definitions today, but by no means the only one:

“Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.”

Certain aspects of this definition deserve to be highlighted. First, sexual health is not merely the absence of disease, dysfunction or infirmity. The other aspect is that sexual health may not be attained without the respect, protection and fulfillment of sexual rights.

Sexual Rights

The agenda for sexual rights emerged at two world conferences: the International Conference on Population and Development (ICPD) of 1994, and the Fourth World Conference on Women (FWCW) of 1995. The Beijing Platform for Action (1995) defined sexual rights in the following terms:

“The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence” (para. 96).

Though a great achievement for the recognition of sexual rights, this definition was not a complete victory, and the quest for legitimacy continues. Petchesky and others, for instance, criticize this definition for “bracketing” sexual rights and conflating them with reproductive rights (Miller, 2000; Petchesky, 2006).

WHO (2004) defines sexual rights as the right of all persons, free of coercion, discrimination and violence to: the highest attainable standard of sexual health, including access to sexual and reproductive health care services; seek, receive and impart information related to sexuality; sexuality education; respect for bodily integrity; choose their partner; decide to be sexually active or not; consensual sexual relations; consensual marriage; decide whether or not, and when, to have children; and pursue a satisfying, safe and pleasurable sexual life.

Though it has been stated that sexual rights are not new rights, but rather the existing rights applied to sexuality (Klugman, 2000), sexual rights pose a problem where there is no consensus regarding certain aspects of sexuality. One example where controversy is still rife is sexual orientation. Horn (2006), for instance, reminds us that Africa in general is hostile to sexual expression that is not heterosexual. It is thus not

surprising that feminists, gays and lesbians, and other marginalized groups have been in the forefront in the struggle for recognition of sexual rights (Eager, 2004). Their political agenda, being perceived as subversive to mainstream thinking about sexuality, has usually met fierce resistance (Long, n.d.). It is therefore not surprising that confronting the stigma of asexuality may raise similar challenges.

Disability and Sexuality: The Dis-ease

Persons with disabilities face the stigma of asexuality. An exploration of this stigma and how it affects persons with disabilities enables an appreciation of the challenges persons with disabilities face. This discussion also reveals the uneasiness of human rights instruments and disability movements to affirm sexuality of persons with disabilities.

Stigma

The stereotype that ascribes asexuality to persons with disabilities is a general phenomenon in society. Following from the definition of sexuality, asexuality could mean lack or deficiency to express or experience any one or more of the elements constituting sexuality.

The stigma of asexuality has adverse effects on the sexual well being of persons with disabilities. Shakespeare, Gillespie-Sells, & Davies (1996) in their groundbreaking book have given an insightful account of the impact of this denial of sexuality on persons with disabilities. Persons with disabilities face various hindrances to their sexuality. This includes lack of sexual self-esteem, failure to enjoy pleasurable sex, and failure to get sexual partners (Tepper, 2000; Yoshida, 1999). Their access to sexual expression may be limited or excluded (Shuttleworth & Mona, 2002; Wade, 2002). They generally experience higher levels of sexual abuse (Naidu, Haffejee, Vetten, & Hargreaves, 2005). They are thought of as incapable of consenting to sexual relationships so that they are on one hand protected by the law from sexual abuse, but on the other denied sexual relationships (Evans & Rodgers, 2000). The health care system or other institutions may fail to address their sexual health needs (Kvam & Braathen, 2006).

Weeks reminds us that sexuality is socially regulated by traditional mores, customs, and other non-state systems (1998). However, legal and social policies play a role in shaping sexuality. Generally, it is only when sexuality is perceived as a problem that policy and law make appearance, as in the case of homosexuality, the sexuality of persons with mental disabilities, and under-age sex. Regulation of sexuality appears in the form of protecting vulnerable individuals from undesirable and unwanted sexual experiences, through criminal legislation, sex education policies, and disability policies (Carabine, 2004).

Where policy and law maintain silence on sexuality, it may not necessarily mean that they are not regulating sexuality. Rather, argues Shildrick (2007), the silence may imply the assumption of dominant constructions of sexuality. Silence may actually

actively construct persons with disabilities as asexual. The dominant construct posits as the norm the heterosexual relation between two putatively equal adults, whose sexual practice is primarily genital based, procreation oriented, and privately conducted (Shildrick, 2004).

Shildrick therefore argues that social and legal policies always have some form of regulation on sexuality. Generally, persons who exhibit sexuality that conforms to heteronormativity have the benefit of the positive aspects of this social regulation.

Due to disability, persons may have a body morphology or mental ability that makes them unable to conform to heteronormativity. For instance, they may be unable to experience genital effect or verbally communicate their needs and desires. They may not be able to conceive. Their sexual organs may not be fully functional, or they may need physical support to be able to engage in sexual activity (Shildrick, 2004). When the sexual practices of persons fall outside the normative range then their sexuality is not legitimized or recognized (Shuttleworth, 2007a).

The stigma of asexuality will depend on the kind and extent of disability. It is not merely that the disabled body may not be aesthetically appealing according to social meanings of attractiveness, though that may be part of the reason persons with disabilities experience stigma. However, a major determining factor of the stigma is the extent to which the physical or mental disability has the potential to, or actually challenges the dominant norms governing sexuality. When disability subverts the heteronormative values and hegemonic masculine expectations (Shuttleworth, 2007a) of society, it is bound to be stigmatized. Wilkerson (2002) says:

“If heterosexual vaginal intercourse is taken as the norm, the sexual practices of many will not seem to count as sex at all. Knowledge of diffuse male sexualities may be culturally suppressed, or even incomprehensible, because they are perceived as incompatible with masculinity, while for women such pleasures are perceived as outside the domain of legitimate heterosexual experiences. The repercussion for those with physical disabilities, like many others, may be silence and unintelligibility, their sexualities rendered incoherent, unrecognisable to others or perhaps even to themselves, a clear instance of cultural attitudes profoundly diminishing sexual agency and the sense of self and personal efficacy which are part of it” (p. 48).

Stigma is stronger when disability is more severe. It should also be realized that oppression based on this stigma intersects with other oppressions such as gender, age, socioeconomic status and race (Shuttleworth, 2007a). However, the current essay is pitched at a general level and will therefore not delve into these facets of oppression.

Shildrick (2004) calls attention to the fact that social and legal policies, and sexuality, are mutually constitutive in that they shape one another. In other words, change in how policy constructs sexuality may redefine how persons understand sexuality. Conversely, how persons understand their sexuality may influence policy.

That social policy is constitutive of sexuality is at once a hurdle but also opportunity for negotiation. This is because if persons with disabilities can redefine their sexuality to suit their bodily and intellectual experiences, that reconstruction feeds back into how the wider society understands disability and sexuality, and may challenge society to reconstruct sexual norms (Reynolds, 2007).

By maintaining the dominant discourse of sexuality and suppressing other minority views, social and legal policies perpetuate the stigma of asexuality and exclude persons with disabilities from being regarded as sexual subjects. Maintaining silence about sexuality in sexual health programs of persons with disabilities lends support to the stigma of sexuality.

Disability and Sexuality in Human Rights Instruments

The dis-ease with sexuality as it relates to disability is reflected in human rights instruments. The recently adopted Convention on Rights of Persons with Disabilities (Convention) shies away from portraying persons with disabilities as sexual subjects. The Convention does not explicitly mention sexuality and sexual relationships. The term “sexual” is mentioned in article 25(a) of the Convention, in the context of health and only in conflation with reproductive health. Otherwise it mentions the right of persons with disabilities to marry and have a family, which *prima facie* is a narrower context than sexual relationships.

However, prior to this Convention, the Committee on Social, Economic and Cultural Rights in its General Comment No. 5 (paras. 30 & 31), had stated that laws and social policies and practices should not impede the realization of the rights of persons with disabilities to marry and form a family. Quinn and Degener (2002) noted that:

“Comment No. 5 reiterates Rule 9(2) of the Standard Rules, stating that ‘persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood.’ It then stresses that ‘the needs and desires in question should be recognised and addressed in both the recreational and the procreational contexts’” (section 5.3.4).

It is submitted that the Convention could have addressed sexual relationships as the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (StRE) do. It may be argued that the recognition of the StRE in the preamble incorporates them in the Convention. Nevertheless, the Convention being an important standard-setting document should have expressed this more explicitly and thus affirm persons with disabilities as sexual subjects and bearers of sexual rights.

Human rights instruments have provisions that explicitly recognize the right to sexual health. These include article 25 of the Convention, and article 14 of the Protocol to the African Charter on Human and People’s Rights on the Rights of Women in Africa. Though other provisions do not mention sexual health explicitly, it is submitted that these

incorporate sexual health as well, such as article 25 of the Universal Declaration of Human Rights, article 12 of the International Covenant on Economic, Social and Cultural Rights, article 16 of the African Charter on Human and People's Rights, and article 12 of the Convention on the Elimination of All Forms of Discrimination against Women. Arguably, these provisions bear the closest relationship to affirming sexual well being through the concept of sexual health as defined by WHO. These provisions therefore have an important bearing on sexuality, and guarantee persons with disabilities the right to sexual relationships, activity and pleasure, free of coercion and disease. They refer to other correlative rights articulated in various other human rights provisions. These include the right to access information, communication and information relating to HIV/AIDS and other health issues.

However, the conflation of sexuality and reproduction again suggests heteronormative underpinnings. This may perpetuate stigma against persons with disabilities.

Another caution is that reference to health may also tend to medicalize sexuality of persons with disabilities, for instance the case of male impotence. Much as persons can derive benefit from treatment of impotence, Shuttleworth (n.d.) and others (Tiefer, 1994; Wentzell, 2006) have warned against this being a guise of serving heteronormativity, where the biomedical-driven project is to fix the person's body to fit the heteronormative and masculine morphology.

To reiterate, human rights instruments have tended to maintain silence on sexuality of persons with disabilities. This silence favors constructing persons with disabilities as asexual rather than affirming their sexuality.

Sexuality and Disability Movements

Disability movements around the globe, most especially in the developed countries in Europe and North America, have taken up the struggle for a positive affirmation of sexuality. Claims have been made that governments should fund sexual encounters for them as captured in a news article by *Ananova* ("Danes Provide Prostitutes," n.d). Some organizations have actually facilitated sexual encounters for persons with disabilities (Ilkkaracan & Jolly, 2007).

In contrast to disability movements from the Europe and North America the general trend in Africa is to dwell on the prevention of violence and HIV/AIDS, and less on tackling the stigma of asexuality.

The then Organisation of African Unity (now African Union) in 1999 proclaimed the African Decade of Persons with Disabilities (1999-2009) and adopted the Continental Plan of Action for the African Decade of Persons with Disabilities (Continental Plan of Action). This Continental Plan of Action is an undertaking that aims at bringing the concerns of persons with disabilities on the broader social agenda. In the area of sexual health, an activity that is enjoying prominence and is spearheaded by the African

Secretariat of the African Decade for Disabled Persons is the campaign against HIV/AIDS. A booklet made for the campaign states, “The stigma experienced by persons with disabilities means that they are *less likely to marry and more likely to have several sexual partners* in a series of unstable relationships” (Secretariat of the African Decade of Persons with Disabilities, n.d., p.2) (italics supplied).

The Continental Plan of Action mentions the stigma of asexuality but only in passing. The main subject is HIV/AIDS. The same is also observed in the agendas of regional organizations such as the Southern Africa Federation of the Disabled (SAFOD), which is the umbrella organization for disabled people’s organizations (DPOs) in Southern Africa. At its website, where SAFOD outlines its programs, sexuality is mentioned only under prevention of HIV/AIDS. Sexuality is not a subject that is given prominence in its own right.

In Malawi, the disability movement is spearheaded by the Federation of Disability Organizations in Malawi (FEDOMA), the umbrella organization coordinating the activities of DPOs. While it is doing a great deal to advance the rights of persons with disabilities in areas such as education and employment, it is only just beginning to look at sexuality. As the general trend in Southern Africa, it is predominantly under the theme of HIV/AIDS or reproduction (FEDOMA, n.d.).

However, several recent research projects carried out with the collaboration of FEDOMA, while not directly on sexuality of persons with disabilities, do open up spaces for discussing sexuality.

The first research project concerns the living conditions of persons with activity limitations in Malawi (Loeb & Eide, 2004). This study did not investigate the sexuality of persons with disabilities. However, the following statement by Loeb and Eide is interesting:

“Somewhat surprising, it was found that need for emotional support surpassed economic support when asking for what type of assistance that was needed in daily life. . . . This is important to bear in mind when developing services for people with disabilities, as emotional needs will more readily be neglected when there is so much to do in terms of practical help” (p. 150).

[This is an important observation. Sexual health encompasses psychological and social structures of support. This finding could very well reflect the need to provide emotional support in the area of sexual health amongst other concerns.](#)

[In 2004, a study was carried out](#) designed to explore and understand the sexual and reproductive health needs and experiences of people with disabilities, their perceptions about HIV/AIDS and how best information on HIV/AIDS can be communicated to people with various forms of disabilities (Munthali, Mvula, & Ali, 2004). One observation about this survey is that it assumed heteronormative values. The participants were asked questions about marriage and sexual intercourse with the

understanding that these are the norms. This has the effect of excluding information regarding other ways of experiencing sexuality. Despite this drawback, this survey did elicit a number of issues pertaining to sexuality.

The research revealed issues including failure to establish relationships because of limitations of mobility, speech problems, negotiation of relationships and failing to establish partnerships. Munthali et al. captured some of the underlying reasons: "... It is extremely difficult for persons with disabilities to establish intimate relations with those who are not disabled because people with disabilities are generally viewed as useless and unproductive" (p. 67).

The research found that 55.9% of the research subjects had difficulties forming sexual relationships for reasons such as fear of HIV/AIDS, fear of pregnancy, and feeling shy. The report concluded that most of the responses were related to the individuals' negative perceptions of themselves.

Evidence from other research elsewhere indicates that young people with disabilities experience rejection from adults and peers, and exclusion from information sharing regarding sexuality (Motangolingoane-Khau, 2006). Other research reveals how the stigma of asexuality damages sexual self-esteem of young disabled persons (Potgieter & Khan, 2005).

In general, there is shying away from confronting the stigma of asexuality in Africa. There may be several reasons for this. One reason is that sexuality is taboo and to bring up the topic for discussion in public, even for persons who are non-disabled, causes discomfort (Malawi Human Rights Commission, 2006). On the other hand, might it be that what Shakespeare (2000) says holds true for Africa as well?

"I think that sexuality, for disabled people, has been an area of distress, and exclusion, and self-doubt for so long, that it was sometimes easier not to consider it, than to engage with everything from which so many were excluded. Talking about sex and love relates to acceptance on a very basic level—both acceptance of oneself, and acceptance by significant others—and forces people to confront things which are very threatening, given the abusive and isolated lives of many disabled people. As Anne Finger suggests 'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction'" (p. 160).

Another reason may simply be that sexuality is not considered as important in the light of other concerns that are thought to be more pressing such as poverty, education and employment. If this is the contention, perhaps the following reflection by Crow cited in Shakespeare et al. (1996) may begin to challenge this thinking:

“I’ve always assumed that the most urgent disability civil rights campaigns are the ones we’re currently fighting for – employment, education, housing, transport etc., etc., and that next to them a subject such as sexuality is almost dispensable. For the first time now I’m beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we’re looking for... It’s not that one area can ever be achieved alone – they’re all interwoven, but you can’t get closer to the essence of self or more ‘people-living-alongside-people’ than sexuality can you?” (p.206).

In order to advance sexual health for persons with disabilities, such as prevention of sexually transmitted infections, it is necessary to find ways and means of confronting the stigma of asexuality, and to affirm the sexuality of persons with disabilities.

Integrated Sexual Health Care

Sexual Access

When considering sexual health care for persons whose disabilities attract the stigma of asexuality, Shuttleworth argues that we must focus on what is central to the sexual needs of persons with disabilities. He introduces the concept of sexual access as a tool for focusing the discussion on sexuality (and sexual rights) of persons with disabilities.

The concept is premised on the recognition that first and foremost, the stigma of asexuality places restrictions on persons with disabilities in their attempt to negotiate sexual relationships with others (Shuttleworth, 2007a). However, sexual access is not just about physical intimacy. Shuttleworth and Mona (2002) say that, “By sexual access we do not mean access to physical intimacy per se. Rather, we mean access to the psychological, social and cultural contexts and supports that acknowledge, nurture and promote sexuality in general or disabled people's sexuality specifically” (p. 3).

The inability of society to nurture the sexuality of persons with disabilities hinders sexual access and results in poor sexual self-esteem (Shakespeare, 2000).

Sexual access can be broken down into two aspects. The first aspect of sexual access is the psychological, social and cultural supports that acknowledge and nurture sexuality and the individual’s need for sexual expression and intimate relationships. The second aspect of sexual access encompasses the opportunity for an encounter with the other. The person should have the opportunity to access the social and interpersonal space in which mutual desire is evoked and sexual negotiations become possible (Shakespeare, 2003).

The notion of supporting sexual access of persons with disabilities may bring up controversial issues with potential to evoke highly emotionally charged discussions within, without and across the disabled and non-disabled communities. These include facilitated sex (Davies, 2000; Shuttleworth, 2007b; Tepper, 2006) and sexual surrogacy

(Shapiro, 2002). Despite the controversies and dis-ease these ideas may churn, Shildrick (2004) comments that:

“Whether you are able-bodied or disabled, you may find the idea of facilitated sex shocking, commendable or immoral... One thing is sure: however we view the dilemmas, the idea of facilitated sex does force us all to acknowledge the sexuality of disabled people” (p. 153).

The sexuality of persons with disabilities may therefore not be ignored because certain norms are challenged by the concept of sexual access. At stake is the humanity of persons with disabilities. They are sexual subjects too. They have sexual rights.

Sexual Health Programming

Sexual access should be the guiding concept in sexual health programs for persons with disabilities. Sexual access keeps us aware that persons with disabilities wish to pursue their fullest sexual health, through sexual expression and experience, and not merely to avoid contracting sexually transmitted diseases and infections. Sexual health programs should respect the full sexual and reproductive rights of persons with disabilities. This could include strong presence of counseling components to help persons with disabilities negotiate the barriers of sexual access of which the stigma of asexuality is the greatest.

Health programming should also accept the full implications of sexual health that includes diversity of experiences and expressions of sexuality. The health sector should train health practitioners who are sensitive to the needs of persons with disabilities especially in the area of sexuality. It may not be easy to achieve full sexual access for persons with disabilities, but the health system can certainly reduce the stress, which persons with disabilities may actually meet pertaining to their sexual health.

Perhaps the greatest challenge is to get persons with disabilities to start appreciating their own sexuality needs, and to be able to express them in an environment where these concerns will be appreciated and their sexuality affirmed. The health system should be the leader in providing such an environment.

Conclusion

Though HIV/AIDS is indeed one of the greatest public health challenges, when it comes to persons with disabilities, dealing with the stigma of asexuality may be as important as dealing with HIV/AIDS. It must always be kept in mind that in the end, HIV/AIDS is one aspect of sexual health, and attaining sexual health is not just avoidance of HIV/AIDS or dealing with this infection. Sexual health will be attained by paying attention to all aspects of sexual health including dealing with the stigma of asexuality. Sexual health will be attained by respecting sexual rights.

Persons with disabilities seek a full experience and expression of sexuality and should not be hindered by prejudiced views towards their sexual capacities. However, confronting HIV/AIDS remains one of the greatest challenges under sexual health and for persons with disabilities. This article's emphasis on dealing with the stigma of asexuality does not in the least diminish this fact. It rather seeks to enhance the quality of HIV/AIDS programming for persons with disabilities.

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