

SEXUALITY  
AND  
DISABILITY  
IN THE INDIAN CONTEXT

WORKING PAPER | **TARSHI** 2010



TARSHI believes that all people have the right to sexual wellbeing and to a self-affirming and enjoyable sexuality. This includes people with disabilities. People with disabilities should not be discriminated against or denied services or information.

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# SEXUALITY AND DISABILITY

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# EXECUTIVE SUMMARY

To most people, sexuality and disability seem to be unconnected terrains. However, the reality is that people with disabilities can also be sexual beings with sexual fantasies, feelings and aspirations like anyone else. They are unable to express their sexuality fully not so much because of a disability but because of the restriction of their mobility, negative societal attitudes and the lack of educational, entertainment, social and health services and rights that are available to other people.

*Sexuality and Disability in the Indian Context* presents an overview of the current scenario in India vis a vis sexuality and disability. This working paper is a collation of information and resources based on interviews with people with disabilities and with their parents, teachers, and other care providers. It also draws upon secondary research to examine existing laws and policies relevant to sexuality and disability in India.

At first glance, the scenario appears devastatingly bleak, especially when one thinks of the sheer numbers of people that this country holds and the depressing lack of resources to address everyone's needs. There is an abysmal dearth of sexual and reproductive health services for people with disabilities. But as we found, there is also an encouraging rise in the awareness that people with disabilities have sexual and reproductive rights, and there are examples of what is being done to affirm these rights. Existing services can be tweaked with very little extra expenditure – much can be done with a little. This paper also offers some ideas for the way ahead. We hope that it will be a useful document for people with disabilities, activists, care providers, health professionals, academicians, researchers, and policy makers to take the work of affirming the sexual and reproductive rights of people with disabilities forward.

# INTRODUCTION

There is now a burgeoning engagement with disability and sexuality in India. This engagement is being spearheaded by different individuals and groups, including disability rights activists, sexual and reproductive rights activists, care providers of people with disabilities and professionals working in the field of disability. Given that work on sexuality itself is fraught with challenges, addressing the sexuality concerns of people with disabilities is no easy undertaking, and it is thanks to all these people that there is a nascent debate on these issues.

Historically, persons with disabilities have been regarded by society in two contradictory ways – either as asexual or as sexually threatening. By and large, their sexual desires are assumed to be non-existent. Most literature related to disability fails to mention sexuality, and sexual and reproductive health related issues.<sup>1</sup> The sexual and reproductive rights of persons with disabilities have not been adequately addressed unlike their other rights to social integration, education or employment (that are at least mentioned, if not implemented in full).<sup>2</sup>

As Renu Addlakha, a social scientist and disability rights researcher currently at the Centre for Women's Development Studies in New Delhi says, "Sexuality is an area of distress, exclusion and self-doubt for persons with disabilities."<sup>3</sup> Few Indian disability rights activists have been able to raise the difficult issue of sexuality. The reasons for this are many and complex.

All over the world, there is a dearth of information related to people with disabilities. Information of every sort – demographic, social, economic, health, the general context of their lives – is scarce. Information about existing sexuality and sexual and reproductive health related initiatives in the context of disability is even scarcer. This is particularly true of

<sup>1</sup> ALBRECHT, G. L. 2005. Encyclopaedia of Disability. University of Chicago. Sage Publications.

<sup>2</sup> NISHA. 2006. Regulation of Disabled Women's Sexuality. InfoChange Agenda. Available at <http://infochangeindia.org/200602105630/Agenda/Claiming-Sexual-Rights-In-India/Regulation-of-disabled-women-s-sexuality.html>

<sup>3</sup> ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India. Occasional Paper No.46. Centre for Women's Development Studies, New Delhi.

India. People who are working on these issues often do so in isolation and may be unaware of other similar initiatives. There are very few studies conducted on sexuality and disability, and these too are not widely publicised. With this in mind, we asked ourselves: What is the current scenario regarding sexuality and disability in India?

This working paper is a collation of information and resources on issues related to sexuality and disabilities. Based on interviews with people with disabilities and with parents, teachers, and other care providers, as well as drawing on secondary research to examine existing laws and policies, this paper presents the current scenario and points to some ways forward. This paper is an attempt to lay out some of the key concerns that have emerged in the course of our work. We hope that it will be a useful document for people with disabilities, activists, care providers, health professionals, academicians, researchers, and policy makers.

In India, the sexuality concerns of people with disabilities are rarely acknowledged and therefore have not been considered an important area for study or research. We recognise that we cannot do justice to the complexities and the complete range of sexuality, sexual and reproductive health related concerns faced by people with all kinds of disabilities in India. For the purpose of this paper, we have focused mainly on people with physical disabilities. We acknowledge the importance of talking about sexuality and identifying the challenges and strategies for working on sexuality with people with different disabilities but were unable to find sufficient research or information about disabilities other than physical disabilities.

We are acutely aware that we may be reinforcing the marginalisation of people with intellectual disabilities, however we had to restrict the scope of this paper due to the lack of first person accounts (other than those we have from our own interactions with care providers of people with multiple disabilities), data and research available on people with intellectual disabilities and sexuality.

# UNDERSTANDING SEXUALITY

## Sexuality in India

Sexuality is an extensive term that covers a range of issues. It includes not only sexual behaviour but also sexual identity, gender identity, sexual orientation, roles, personality, relationship patterns, thoughts, feelings, attitudes etc. It also includes the social, ethical, moral, cultural and spiritual concerns of an individual. Multiple factors are influenced by and influence one's sexuality. Everyone does not experience sexuality in the same way. Being aware of these differences helps cater to individual needs and provide effective services to people.

Sexuality is still largely considered a taboo field in India and many parts of South Asia although newer spaces are gradually opening up to voice and address sexuality concerns. Sexuality is managed and moderated through societal rules, regulations, norms and ideals in this region, as it is, in different ways, in other parts of the world.

Sexuality concerns are publicly addressed in Indian society primarily in the context of abuse, violence and the unwanted negative consequences of unsafe sex such as infections and unwanted pregnancies. While these are no doubt important to address, sexuality is not only about the prevention of disease or abuse, it is much more. Sexuality is also as much about intimacy, relationships, self-expression, self worth, pleasure and eroticism. All people have the right to sexual wellbeing, but more often than not, people with disabilities are regarded not only as sexless but also often not even as people.

## Defining Sexuality

Sexuality means different things to different people. For some people it could mean the act of sex and sexual practices, for others it could

mean sexual orientation or identity and/or preference and yet for others it could mean desire and eroticism. Sexuality encompasses many ideas and has many facets. The definition of sexuality has been evolving along with our understanding of it. There are a number of definitions that cover various components of sexuality. While there is no single agreed upon definition, here is the WHO draft working definition of sexuality (2002) that is broadly accepted:

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. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.<sup>4</sup>

## Defining Sexual and Reproductive Health and Rights

**Reproductive Health** is defined as a state of physical, mental, and social wellbeing in all matters relating to the reproductive system at all stages of life. Reproductive health implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when, and how often to do so. Implicit in this are the rights of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, and the right to appropriate health-care services that enable women to safely go through pregnancy and childbirth.<sup>5</sup>

**Reproductive Rights** are the rights of men and women to be informed and to have access to safe, effective, affordable and acceptable methods

<sup>4</sup> WORLD HEALTH ORGANIZATION. 2006. Defining Sexual Health: A Report of a Technical Consultation on Sexual Health, 28-31 January, 2002, Geneva. Available at [http://www.who.int/reproductivehealth/topics/gender\\_rights/sexual\\_health/en/](http://www.who.int/reproductivehealth/topics/gender_rights/sexual_health/en/)

<sup>5</sup> UNITED NATIONS POPULATION FUND. Reproductive Rights and Reproductive Health. Programme of Action of the International Conference on Population and Development. Available at <http://www.unfpa.org/icpd/icpd-programme.cfm#ch7>

<sup>6</sup> UNITED NATIONS POPULATION FUND. Reproductive Rights and Reproductive Health. Programme of Action of the International Conference on Population and Development. Available at <http://www.unfpa.org/icpd/icpd-programme.cfm#ch7>

<sup>7</sup> WORLD HEALTH ORGANIZATION. 2006. Defining Sexual Health: A Report of a Technical Consultation on Sexual Health, 28-31 January, 2002, Geneva. Available at [http://www.who.int/reproductivehealth/topics/gender\\_rights/sexual\\_health/en/](http://www.who.int/reproductivehealth/topics/gender_rights/sexual_health/en/)

of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant.<sup>6</sup>

**Sexual Health** is a state of physical, emotional, mental and social wellbeing in relation 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.<sup>7</sup>

**Sexual Rights** embrace human rights that are already recognised in national laws, international human rights documents and other consensus statements.

Sexual rights include 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.

The responsible exercise of human rights requires that all persons respect the rights of others.<sup>8</sup>

These rights are not the exclusive domain of any specific group and should be accessible to all; this includes people with disabilities.

<sup>8</sup> WORLD HEALTH ORGANIZATION. 2006. Defining Sexual Health: A Report of a Technical Consultation on Sexual Health, 28-31 January, 2002, Geneva. Available at [http://www.who.int/reproductivehealth/topics/gender\\_rights/sexual\\_health/en/](http://www.who.int/reproductivehealth/topics/gender_rights/sexual_health/en/)

# UNDERSTANDING DISABILITY

## Models of Disability

Like sexuality, the concept of disability has also evolved with time. It has been viewed from different perspectives over the decades.

The moral model views an impaired body as the result of sins or misdeeds in this or a previous life, as a consequence of either one's own misdeeds or those of close relatives, particularly of the mother. It is historically the oldest model and is less prevalent today. However, there are still many cultures that associate disability with sin, shame and guilt even if these are not overtly based on religious doctrine. For the individual with a disability, this way of thinking is particularly burdensome. This model has been associated with shame on the entire family of a person with a disability. Families have hidden away disabled family members, keeping them out of school and excluded them from any chance at playing a meaningful role in society. Even in less extreme circumstances, this model has resulted in general social ostracism and self-hatred.<sup>9</sup>

<sup>9</sup> KAPLAN, D. The Definition of Disability. Available at <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>

<sup>10</sup> ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India. Occasional Paper No.46. Centre for Women's Development Studies, New Delhi.

In India, disability is seen as bad karma. As Renu Adlakha says, "Indeed the law of karma decreed that being disabled was the just retribution for past misdeeds. Pity, segregation, discrimination and stigmatisation became normalised in the management of persons with disabilities. Such constructions of the disabled by the non-disabled have the dual effect of not only justifying the complete marginalisation and disempowerment of a whole population group but also leading to the internalisation of such negative stereotypes by disabled persons themselves."<sup>10</sup> This is a crucial point that we will come back to later in the paper.

The charity or welfare model of disability views the person with disabilities as the problem and dependent on the sympathy of others to provide assistance in a charity or welfare model.<sup>11</sup> This is the philosophy of a number of disability organisations in India even today.

The medical model looks at disability as a defect or sickness which has to be cured through medical intervention. It regards disabled people as bodies that are damaged, broken and being unable to match or fit the norm or 'ideal' body type. Thus, the medical model regards the body of a person with disabilities as pathological. It also looks at disability as a personal tragedy of the person affected by it, which if at all, can only be cured by medicines.<sup>12</sup> Medical interventions focus on repairing the body to make it fit the prevalent notion of the body in society, often disregarding what disabled persons themselves feel or want.<sup>13</sup>

The rehabilitation model is highly influenced by the medical model and believes that disability is a deficiency that must be fixed by rehabilitation professionals or other helping professionals. It focuses on therapies, exercises and special care to help people with disabilities overcome their constraints and approximate the ideal body.<sup>14</sup>

The social model makes a distinction between 'impairment' and 'disability'. It defines impairment as 'lacking part or all of a limb or having a defective limb, organism or mechanism of the body.' On the other hand, disability is 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities.'<sup>15</sup>

The social model takes disability away from the individual alone and places the responsibility on society as a whole. It argues that disability is a result of social structures, not deficits in the body or brain. The present social structures – predominantly shaped by people's attitudes and understanding of disability – deny access to resources and information which disables an individual. The social model argues that people with disabilities are not victims but agents resisting oppression, overcoming challenges and thereby changing social structures.<sup>16</sup>

<sup>11</sup> WORLD BANK REPORT. 2007. People with Disabilities in India: From Commitments to Outcomes. Available at [http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607\\_20071121124147/Rendered/PDF/415850IN0Disab1or t0NOV200701PUBLIC1.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607_20071121124147/Rendered/PDF/415850IN0Disab1or t0NOV200701PUBLIC1.pdf)

<sup>12</sup> KAPLAN, D. 'The Definition of Disability'. Available at <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>

<sup>13</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women's Health Training Research and Advocacy Cell (WOHTRAC), M. S. University, Baroda, Vadodara.

<sup>14</sup> KAPLAN, D. The Definition of Disability. Available at <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>

<sup>15</sup> BIID Info. 2007. Impairment vs. Disability. Available at [http://biid-info.org/Impairment\\_vs.\\_Disability](http://biid-info.org/Impairment_vs._Disability)

<sup>16</sup> SHAKESPEARE, T. 2000. Disabled Sexuality: Towards Rights and Recognition. Available at <http://www.bentvoices.org/culturecrash/shakespeare.htm>

The rights-based model of disability builds on the insights of the social model to promote creation of communities which accept diversities and differences, and have a non-discriminating environment in terms of inclusion in all aspects of the life of society.<sup>17</sup> According to this model all human beings irrespective of their disabilities have rights, which are unchallengeable. This model emphasises viewing persons with disabilities as subjects and not as objects thus locating the problem outside disabled persons and addresses the manner in which the economic and social processes accommodate the differences of disability or not, as the case may be.<sup>18</sup>

<sup>17</sup> WORLD BANK REPORT. 2007. People with Disabilities in India: From Commitments to Outcomes. Available at [http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607\\_20071121124147/Rendered/PDF/415850IN0Disab1or t0NOV200701PUBLIC1.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607_20071121124147/Rendered/PDF/415850IN0Disab1or t0NOV200701PUBLIC1.pdf)

<sup>18</sup> BHANUSHALI, K. 2007. Changing Face of Disability Movement: From Charity to Empowerment. Available at <http://ssrn.com/abstract=965999>

The cultural model sees disability as a pervasive system that, through its stigmatisation of certain bodily variations, informs our notions of self, structures institutions and identities, informs cultural and political practices and constitutes sexuality. Feminist disabilities studies theorist Rosemary Garland-Thomson summarises it when she argues:

- first, it is a system for interpreting and disciplining bodily variations;
- second, it is a relationship between bodies and their environments;
- third, it is a set of practices that produce both the able-bodied and the disabled;
- fourth, it is a way of describing the inherent instability of the embodied self.<sup>19</sup>

<sup>19</sup> GARLAND-THOMSON, R. 2002. Integrating Disability, Transforming Feminist Theory. *National Women's Studies Association Journal*, 14, 2, (Fall 2002), 1-32.

Let's consider how each of these might play out. By interpreting bodily variations as being desirable or undesirable and devaluing particular variations, the notion of a particular self is created and internalised. Take body shape as an example. In cultures where voluptuous women are thought to be desirable and are sought after, skinny is a bad word. The converse holds true in 'size zero' cultures. In the world of able-bodied people, people with a disability are constituted as incomplete and therefore not capable of partaking in the full range of human experience. Just because a deaf woman cannot experience the glories of

music, it does not follow that she cannot experience the glories of sex.

Our bodies are in constant relationship with our environments and most times we provide only for particular types of relationships. So for example, to get to an office one might need to take a bus. What if the roads and the buses are not accessible to a wheelchair user? What if the office is on the third floor and has no lift? When it comes to sexuality, some people with disabilities might need extra pillows or some assistance in adopting sexual positions, or simply information provided in other modalities such as Braille or sign language.

Practices produce ability. Look at a simple but common example to understand this. In certain countries where the average person is tall, short people are challenged by their verticality in performing the simplest of daily tasks: holding on to the overhead bus rail, reaching the shower head to angle it the right way, bolting or opening a door with overhead bolts. Why? Simply because the practice is geared for the convenience of tall people. Similarly, most public spaces are not accessible to people with disabilities. But if all buildings, including schools, shopping malls, hospitals, clinics and museums were wheelchair accessible, people using wheelchairs would be 'able' to be much more a part of public life.

Garland-Thomson's fourth point means that what we think of our self, lives in a body. That body is not stable, however much we may want to think of it that way, because it is not immune to injury or illness that can suddenly cause an impairment that manifests as disability. This is reflected in the bodies of people who have had a spinal injury in an accident, for example. From being people who may have enjoyed a range of sexual pleasures, they may become people who have very little or no sensation in their genitals and over time, discover other zones of erotic sensation in their bodies.

According to Janet Price, who is a feminist and disabled campaigner from Northern England, an Honorary Research Fellow at the Liverpool School of Tropical Medicine and co-editor of *Feminist Theory and the Body: A Reader* (1999) with Margrit Shildrick, Western research

on sexuality and disabilities has been conducted from different approaches:

- a the medical approach, as seen in research on physical medicine and rehabilitation where techniques have been adopted that have been found to help men with spinal cord injuries to have erections, for example
- b the historical approach that looks at how people with disabilities have been treated and sexuality has been regarded in past
- c the rights based approach that addresses, for example, sexual violence and/or abuse faced by people with disabilities
- d the feminist approach that analyses information about sexuality and disability to understand how the two interact in the context of social structures.<sup>20</sup>

<sup>20</sup> Janet Price. 2009. Personal communication.

People with disabilities themselves may view disability using any of the models described above, depending upon their social and analytic understanding. The social model has served as a powerful tool in making people with disabilities aware of their rights and fighting to overturn the barriers created by the dominant attitudes of society, professionals, and policy makers as well as architectural, sensory, cognitive and economic barriers. The tendency to regard disability and people with disabilities in a homogeneous way overlooking the variations within the disability community often leads to the creation of disabling environments.<sup>21</sup>

<sup>21</sup> KAPLAN, D. The Definition of Disability. Available at <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>

By and large, almost all people with disabilities face challenges in accessing information and services related to their sexual and reproductive health concerns as indeed do non-disabled people in our socio-cultural context. The problem is however compounded when the person has severe or multiple impairments.

C. Mahesh from Community Based Rehabilitation Forum (CBR Forum), Bangalore, says, “There is a tendency for field staff to work on issues of

sexual and reproductive health and rights more with persons with milder disabilities – people (especially women) with multiple disabilities, spinal injuries, learning disability, and hearing impairments are most often left out”. Pramada Menon, a feminist and queer activist, reflects from her experience that while working on issues of sexuality for people with disabilities, it is usually assumed that one is talking about persons with physical disabilities which are not of a severe degree. This is related to societal discomfort with engaging with people with severe disabilities in a meaningful manner by and large. The more severe a person’s disability, the more the discomfort in engaging with them as well as in addressing their sexuality related concerns. She says, “I think a lot of us live with the assumption that we are always going to be ‘able’ and that make it difficult for us to look at anything that is not the norm. For instance, just as lesbian, gay, bisexual, transgender and intersex images do not exist anywhere around us and we have to make a concerted effort to create them and bring them into conversations, similar are the issues with disability.”

## Defining Disability

Again like sexuality, disability as a concept is complex and multi-layered. As with any complex construct, there are always problems with definitions. Definitions by their very nature tend to be limiting and often over-simplify ideas in their attempt to offer clarity and focus. Also, in the field of disability, terminology keeps changing as evidenced by the shifts in language for example, handicapped persons, people with special needs, challenged people, disabled persons, people with disability, and so on, reflecting the politics of the day.

According to the World Health Organisation (WHO), “Disabilities are an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.”<sup>22</sup>

<sup>22</sup> WORLD HEALTH ORGANIZATION. Disabilities. Available at <http://www.who.int/topics/disabilities/en/>

According to Article 1 of the United Nations Convention on Rights of Persons with Disabilities (2006) “Persons with Disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

In India, the Persons with Disabilities Act (Equal Opportunities, Protection of Rights and Full Participation), 1995, says that “Person with disability means a person suffering from not less than forty per cent of any disability as certified by a medical authority.” This has been criticised as being very limiting and narrow in focus and leaving out a number of conditions from the purview of disability. There is more on this in the next section.

According to Anita Ghai, a well-known disability rights activist and a lecturer at the University of Delhi, both the WHO definition and the one in the 1995 Indian Act, “... do not reflect the definitions propounded by disabled people themselves. As early as 1976, the Union of the Physically Impaired Against Segregation (UPIAS), expressed a need for an alternative definition of disability.”<sup>23</sup> The UPIAS definitions are as follows:

<sup>23</sup> GHAI, A. 2003. (Dis) Embodied Form: Issues of Disabled Women. Shakti Books, New Delhi.

**Impairment:** lacking part or all of a limb, or having a defective limb, organism or mechanism of the body.

**Disability:** the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have physical impairments, and thus excludes them from the mainstream of social activities.

While working on issues of disability it goes without saying that it is important to be aware that there are many different types and degrees of disability. Broadly, there are three degrees by which disability is evaluated: mild, moderate and severe. There are also individuals who may have more than one disability, for example, intellectual disability and cerebral palsy. Therefore, disability is not a simple phenomenon

and cannot be categorised in fixed ways. The understanding and the mechanisms to approach specific challenges associated with specific disabilities will have to be tailored according to the specific requirements of each individual. In fact two people with the same kind and degree of disability can have very different needs from one another. Individual differences stem from various factors including but not limited to one's gender, class, caste, religious and cultural background. Just as in the case of disability, sexuality and sexual and reproductive health related needs of no two people are exactly alike. This can be very challenging for professionals and service providers in the field.

In present day India, there is a shift in thinking by and large by disability rights activists from a welfare/charity approach to a social model and even to a rights based approach. On the other hand, society at large and people with disabilities themselves may still subscribe to the fate/moral/charity and medical/rehabilitation models.

Anita Ghai goes on to say, "The definitional riddles in disability are extremely significant as they decide the fate of the person designated as disabled." She says that her understanding is that disability is not really a fixed category most clearly signified by the white cane user or a crutch user. Rather, it denotes a fluid and shifting set of conditions.<sup>24</sup>

<sup>24</sup> GHAI, A. 2003. (Dis) Embodied Form: Issues of Disabled Women. Shakti Books, New Delhi.

With regards to defining mental illness, Shampa Sengupta, a disability rights activist and Director of the Sruti Disability Centre in Kolkata says, "Firstly, it is difficult to define 'mental illness'. 'Madness', 'lunacy', 'insanity', 'mental illness' and 'mental disorder' are terms used to describe aspirations, beliefs and conduct that vary from the accepted psycho-social or bio-medical norm. We are careful about using the politically correct terminology for the mentally ill today. But without changing the situation on the ground, changing the terminology is a futile exercise." She goes on to say that "Societal attitudes reflect the terms we use. Someone with a psycho-social disability is looked down upon by society. Despite mental illness being included as a category of disability in the Persons with Disabilities Act 1995, reservations under the law exist only for those who are physically disabled. It is clear that even amongst persons with disability, those with psycho-social

problems feature low in the hierarchy. They are not eligible to stand for elections, nor do they have the right to vote. Not only do they not have political rights, according to Indian law they cannot enter into any contract.”<sup>25</sup>

<sup>25</sup> <http://infochangeindia.org/200804117032/Disabilities/Analysis/No-rights-for-the-mentally-disabled.html>

Unfortunately, policy makers draw mostly from the medical and rehabilitation model definitions of disability and therefore disregard any other aspect of life or concern that falls outside this definition.<sup>26</sup>

<sup>26</sup> KAPLAN, D. The Definition of Disability. Available at <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>

Attitudinal barriers are created when it is assumed that people with disabilities are childlike, are unable to make decisions for themselves and are asexual. This denies them their right to privacy, autonomy and bodily integrity, and prevents them from accessing information and sexual and reproductive health services. Infantilising people with disabilities excludes them from decision-making processes and from being involved in planning and implementing programmes meant for them. Conversely, stereotyping all disabled people as ‘perverted’ or ‘oversexed’ perpetuates the belief that they need to be controlled from hurting others.

## People with Disabilities in India

That people with disabilities are not a homogenous group is obvious. There are many kinds of disabilities – physical and developmental. In India the law recognises seven types of disabilities from within a narrow medical context. The experience of disability is unique to every individual and also varies across gender, caste, class, age and the presence of more than one disability. For example, people with mental illness or intellectual disabilities, those with visual, hearing and speech impairment and those with restricted mobility or with so-called ‘medical disabilities’ all encounter different barriers, and have different ways of dealing with them. In addition, two people with the same disability may have differing experiences based on their gender, socio-economic status and age. In other words, as mentioned earlier, the nature of disabilities affects women and men differently, and more so depending on their socio-economic background and age.

Persons with disabilities are devalued because of their capabilities, societal participation or other key aspects of life common in society. Referring to the 2007 World Bank Report *People With Disabilities in India: From Commitments To Outcomes*, we find that negative opinions about the capacity of people with disabilities as effective members of the workforce or the capacity of children with disabilities to be able to participate in regular school is a bigger deterrent towards their development than the disability itself. Disabilities that are more visible (physical disabilities or mental disabilities) are more stigmatised than invisible disabilities (hearing disabilities), thus reflecting a hierarchy of stigma faced by persons with disabilities. Negative societal attitudes also influence the family of persons with disabilities and disabled individuals themselves, leading to low self esteem and self worth.<sup>27</sup>

According to Renu Addlakha, “Historically in India as elsewhere in the world, there has been a deep-rooted cultural antipathy to persons with disabilities. Throughout the ages the disabled have been looked down upon with disdain, almost as if they were subhuman. They have been portrayed as medical anomalies, helpless victims and a lifelong burden on family and society.”<sup>28</sup>

As Anita Ghai points out, “Disability in the Indian context is often understood as a ‘lack’ or ‘deficit’ as well as a ‘difference’. Very few people accept the fact that disability is as much a social construct as, say, gender. Since the normative culture in India and the world over carries existential and aesthetic anxieties about differences of any kind, be it caste, class, gender, race or disability, people who are impaired in any way have to live with markers such as ‘disabled’, ‘handicapped’, ‘crippled’, ‘differently-abled’ and ‘special’. This results in an existence marked by acute marginalisation, discrimination and stigmatisation, and disability appears more as a personal quest and tragedy to be borne alone. Even those of us who have lived and studied in apparently inclusive educational institutions, have felt the intolerant attitude of Indian society towards disability.”<sup>29</sup>

As she says, the popular media also often portrays disability as a ‘lack’ or ‘deficit’ These assumptions, she goes on to say, are rooted in

<sup>27</sup> WORLD BANK REPORT. 2007. *People with Disabilities in India: From Commitments to Outcomes*. Available at [http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607\\_20071121124147/Rendered/PDF/415850IN0Disab1ort0NOV200701PUBLIC1.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607_20071121124147/Rendered/PDF/415850IN0Disab1ort0NOV200701PUBLIC1.pdf)

<sup>28</sup> ADDLAKHA, R. 2007. *Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India*. Occasional Paper No.46. Centre for Women’s Development Studies, New Delhi.

<sup>29</sup> GHAI, A. 2009. *The Women’s Movement Must Do More for Disabled Women*. InfoChange Agenda. Available at <http://infochangeindia.org/200906017769/Disabilities/Analysis/The-women’s-movement-must-do-more-for-disabled-women.html>

the dominant Hindu mythology where in the two most popular epics *Mahabharata* and *Ramayana*, negative characters were attributed some form of deformity for example, Manthara the ‘hunchback’ in the *Ramayana* and Shakuni, the ‘lame’ man in the *Mahabharata*. But, as she says, “At the same time, historically there are also narratives to highlight the belief that people with disabilities are children of God. This positioning provided spaces, in spheres of religion and knowledge, where the ability to transcend the body was a distinct possibility. Even though the implicit meaning of such possibilities may be disturbing within our present understanding of disability, it does indicate a dignified negotiation of difference. Thus, the renowned scholar Ashtavakra who had eight deformities, and the great poet Surdas, who was visually impaired, are illustrations of strength and ability to fight oppression. However within these constructions, disability is something that can be overcome. All the same, the predominant cultural construction of disability is largely negative”<sup>30</sup>

<sup>30</sup> GHAI, A. 2003. (Dis) Embodied Form: Issues of Disabled Women. Shakti Books, New Delhi.

In a patriarchal society, gender exacerbates women’s experience of disability. A report of a consultative meeting on gender and disability concluded that, “Girls and women are more likely to be excluded from education than boys with disabilities; they are less likely to be taken for health care and treatment for their impairment than boys, particularly when money is in short supply; their opportunities for family life are severely compromised, due to societal prejudices against marriage of disabled young women, which can lead either to them remaining unmarried or to their family having to pay large dowries to ‘offset’ the disadvantage of their disability; with limited education, employment opportunities are restricted and even if they are educated, discrimination makes it more difficult for young women to obtain and hold on to jobs; and in many of these contexts – family, school and work – disabled women and girls experience high rates of sexual abuse. As a consequence of a life marked by discrimination, disadvantage and often abuse, most disabled women and girls suffer from low self-esteem and confidence and poor self image.”<sup>31</sup>

<sup>31</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women’s Health Training Research and Advocacy Cell, M. S. University, Baroda, Vadodara.

## Some numbers

In the Indian context, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995<sup>32</sup> states that “*Person with disability* means a person suffering from not less than forty per cent of any disability as certified by a medical authority.” Further, it says, “Disability means -

- i Blindness
- ii Low vision
- iii Leprosy-cured
- iv Hearing impairment
- v Locomotor disability
- vi Mental retardation
- vii Mental illness”

The above classification offers a narrow medical definition of disability which limits the number of people with disabilities to much less than the actual figure. Internationally agreed definitions suggest that people with disabilities constitute at least 10% of the population.<sup>33</sup> As per the statistics provided by the World Health Organisation, people with disabilities constitute 10% of the world’s population. Further, a study by the United Nations Population Fund states that 80% of this population lives in developing countries.<sup>34</sup> However, according to the 2001 Census of India, there are 21.9 million people with disabilities in India who constitute 2.13% of the total population. This includes persons with visual, hearing, speech, locomotor and mental disabilities. 75% of persons with disabilities live in rural areas, 49% of the disabled population is literate and only 34% are employed.<sup>35</sup> According to the National Sample Survey Organisation (NSSO), Government of India 2002 data, numerically, people with orthopedic disability or locomotor disability are in the majority, constituting about 51% of the total population of people with disabilities in India. This is followed by hearing

<sup>32</sup> The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. Available at <http://www.socialjustice.nic.in/pwdact1995.pdf>

<sup>33</sup> MONT, D. 2007. Measuring Disability Prevalence. The World Bank. Available at <http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf>

<sup>34</sup> BARRIER BREAK TECHNOLOGIES. Disability Statistics. Available at <http://www.barrierbreak.com/disabilitystats.php>

<sup>35</sup> DISABILITY INDIA INFORMATION RESOURCES. Facts and Figures. Available at <http://www.disabilityindia.com/html/facts.html>

<sup>36</sup> DISABILITY INDIA INFORMATION RESOURCES. Facts and Figures. Available at <http://www.disabilityindia.com/html/facts.html>

<sup>37</sup> SRIDHAR, L. 2003. 70 Million Disabled in India and Only 2 % are Educated and 1% Employed. InfoChange Agenda. Available at <http://infochangeindia.org/2003060269/Disabilities/Features/70-million-disabled-in-India-and-only-2-are-educated-and-1-employed.html>

<sup>38</sup> WORLD BANK REPORT. 2007. People with Disabilities in India: From Commitments to Outcomes. Available at [http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/1/21/000310607\\_20071121124147/Rendered/PDF/415850IN0Disab1or t0NOV200701PUBLIC1.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/1/21/000310607_20071121124147/Rendered/PDF/415850IN0Disab1or t0NOV200701PUBLIC1.pdf)

<sup>39</sup> WORLD BANK REPORT. 2007. People with Disabilities in India: From Commitments to Outcomes. Available at [http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/1/21/000310607\\_20071121124147/Rendered/PDF/415850IN0Disab1or t0NOV200701PUBLIC1.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/1/21/000310607_20071121124147/Rendered/PDF/415850IN0Disab1or t0NOV200701PUBLIC1.pdf)

impairment constituting 14%, visual impairment 14%, speech disorder 10% and intellectual disabilities 10% in the larger population of people with disabilities.<sup>36</sup> The use of a narrow definition of disability implies that many people are excluded from these surveys. In addition many people with disabilities, especially girls and women with disabilities, may not be counted by officials. This could be due to families hiding the fact that they have disabled members as well as due to the fact that the official definitions leave out a number of disabilities.

The census and NSSO figures are hugely contested by disability rights activists in India. Javed Abidi a well-known disability rights activist and the founder of the National Centre for Promotion of Employment for Disabled People (NCPEDP) claims that India has about 70 million people with disabilities who constitute almost 7% of the total population.<sup>37</sup> In addition, according to the World Bank Report, the official estimates of disability enumerated by the 2001 census are low (around 2%) and alternative estimates using different methods and more inclusive definitions by other agencies like the NSSO suggest a higher incidence of disability (4-8%) in India. Alternative estimates suggest that the actual prevalence of disability in India could be easily around 40 million minimum, and as high as 80-90 million if more inclusive definitions of mental illness and mental retardation in particular were used.<sup>38</sup> Further, the enumeration does not include people with mild and moderate disabilities, leaving a large group out of the final statistics.

The average literacy and education rates amongst people with disabilities are much lower than those of their non-disabled counterparts. Reports suggest 52% illiteracy among people with disabilities against a 35% average for the general population. Illiteracy is high across all categories of disability, and extremely so for children with visual, multiple and mental disabilities (and for severely disabled children of all categories).<sup>39</sup>

Further with reference to employment prospects of people with disabilities, the scenario is again dismal. The employment rate of the disabled population is lower (about 60% on average) than the general population. The World Bank Report reflects that having a disability

reduces the probability of being employed by over 30% for males in rural Uttar Pradesh and Tamil Nadu, with the effect being lower for women. People with disabilities who are better educated like those with post graduation degrees or vocational training, have more prospects of employment than those not educated or trained. Interestingly, people from rural areas, are more able to find employment and are integrated better into society than those in urban areas. People with certain types of disabilities, e.g. hearing, speech and locomotor disabilities, and those with disability since birth also have better chances of getting a job. Mental illness and mental retardation are among the most stigmatised of all disabilities, further pushing down employment prospects even in cases where the disabilities are not severe.<sup>40</sup>

<sup>40</sup> WORLD BANK REPORT. 2007. People with Disabilities in India: From Commitments to Outcomes. Available at [http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607\\_20071121124147/Rendered/PDF/415850IN0Disab1ort0NOV200701PUBLIC1.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607_20071121124147/Rendered/PDF/415850IN0Disab1ort0NOV200701PUBLIC1.pdf)

# DISABILITY AND SEXUALITY IN THE CURRENT SCENARIO

## Does Sexuality Matter?

As is evident, people with disabilities form a significant percentage of India's population. Disability rights activists rightly contend that the actual number of people with disabilities is far more than what is reflected in the census data or other government documents. In spite of such large numbers there is very little research (especially on sexuality) about people with disabilities in India and therefore very little understanding of their specific needs and concerns. This speaks of the invisibility of people with disabilities from mainstream research whether on sexuality or otherwise, almost implying that people with disabilities do not count. The lack of research has led to a gap in policy formulation, strategic designing and planning for advocacy and also in planning intervention programmes and services for people with disabilities in India.

There is a need for more studies to be conducted to assess the needs of people with disabilities in reference to their sexual concerns and desires so that effective interventions can be undertaken. A study by Kevan Moll published in 2007 has looked at issues of HIV and AIDS and disability in India.<sup>41</sup> The study provides an in-depth analysis of the situation of people with disabilities and their vulnerability and access to HIV and AIDS services in India. A paper by Renu Addlakha in 2007 discussed notions of sexual identity among urban Indian youth based on four case studies of college students in Delhi.<sup>42</sup> The study highlights the difficulties of a person with disabilities in finding a partner. Looking at gender differentials the study also reveals that women with disabilities are willing to get married to men with disabilities whereas most men with disabilities would prefer to have a woman who has no disabilities for a wife.

<sup>41</sup> MOLL, K. 2007. Too Few to Worry About? Or too Many to Ignore - The Exclusion of People with Disabilities from HIV Programmes in India. Available at <http://www.cbrforum.in/articles/Disability%20and%20HIV%20Final%20Report.pdf>

<sup>42</sup> ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India. Occasional Paper No.46. Centre for Women's Development Studies, New Delhi.

In the last two decades, people with disabilities have come together in India to push through disability legislation, be included in the census and make representations to the media, among other things. According to Anita Ghai, “Though the pace is slow and the efforts fragmented, nevertheless there is now some visibility for the disabled in a society that tends to largely ignore their existence.”<sup>43</sup>

Globalisation, economic liberalisation, the opening up of the skies to satellite television and the Internet have all been credited with contributing to rapid social change in India over the past two decades. In the context of sexuality, a number of issues are now being openly discussed and addressed. For example, Western soap operas and reality shows (some of which have been adapted to Indian contexts) have brought sex and sexuality into people’s living rooms. In addition, recent TV debates and news coverage regarding sexuality education in schools and the Delhi High Court ruling on reading down Section 377 of the Indian Penal Code that criminalised same-sex sexual behaviour has also led to these issues becoming the subject of dining-table conversations. Paradoxically however, sexuality is still kept largely under wraps, especially so for people with disabilities who in the popular imagination are not considered as sexual beings.

In societies where there is a premium on beauty, youth and fitness, people with visible disabilities are particularly stigmatised. The more ‘different’ they look from the ‘ideal’ as projected through the mass media and films, the more is the discrimination and stigma they encounter. In society’s collective illusion and idealisation of the ‘perfect’ body, a person’s visible disability gets the most attention and their other aspects as individuals are ignored. So for instance, a person with one hand or leg is seen as a person without a limb rather than a human being with desires, hopes, fears and longings like anyone else.

Parents and care providers are faced with the challenge of addressing sexuality related concerns of their young children with disabilities which often bring home the reality of their children as sexual and reproductive beings. This can be hard to accept if families and societies have been denying this aspect of young people with disabilities.

<sup>43</sup> GHAI, A. 2009. The Women’s Movement Must Do More for Disabled Women. InfoChange Agenda. Available at <http://infochangeindia.org/200906017769/Disabilities/Analysis/The-women’s-movement-must-do-more-for-disabled-women.html>

For most parents of children with disabilities in India the experience of bringing up the child is not an easy one. The State does not provide many resources or services and society in general stigmatises the child and the family. Most commonly, it is parents of girls with disabilities, who are concerned about managing menstruation and safeguarding their daughters from abuse. Parents of adolescent boys with disabilities worry about controlling activities such as masturbation and inappropriate touching of either the boys' own or others' body parts.

Madhumita Puri from the Society for Child Development shared from her experience of working with children and young adults with intellectual disabilities that parents do not want to acknowledge their children's sexuality concerns. Parents begin talking about these issues only when the children start growing up and exhibiting so-called undesirable behaviour in public; their concern is often from a problem-solving approach and not from the perspective of addressing sexual desires. With limited resources and negative societal attitudes to sexuality, often parents who want to address the sexuality concerns of their growing or adult children with disabilities do not have any services that they can access. She believes that it is important to work with the immediate environment like family, care providers, teachers and also other staff members of institutions and schools to tackle this issue.

WOHTRAC (Women's Health Training Research and Advocacy Cell), an organisation based in Vadodara, Gujarat has been working for nearly a decade to promote a holistic perspective and a wider definition of women's health. From its years of experience of working on issues of women's health especially reproductive health, WOHTRAC found that disabled women do not feature in the women's health discourse. They therefore decided to include disability and gender as a thematic area in their perspective and capacity building activities. As a part of this they organised a one day Consultative Meet to Design a Perspective Building Workshop on Gender and Disability in 2004 which was moderated by Janet Price. As part of the same meeting, a needs assessment appraisal was conducted among organisations which involved people working with disability in Vadodara city. The assessment revealed that of the 12 main areas of concern for people with disabilities, issues around

sexuality was listed the last. The other main areas of concern were to treat people with disability as a ‘special group’, ‘strategies and models of intervention for rehabilitation’, ‘understanding needs and causes of different forms of disability’ to name a few. Sexuality concerns of those with disabilities were not the main concern or a priority area for many who were working on issues of disability or even reproductive rights.<sup>44</sup>

As the recently released WHO and UNFPA document *Promoting Sexual and Reproductive Health for People with Disabilities* says, “Like everyone else, persons with disabilities have SRH needs throughout their lives, and these needs change over a lifetime. Different age groups face different challenges. For example, adolescents go through puberty and require information about the changes in their bodies and emotions, and about the choices they face concerning sexual and reproductive health related behaviour. Adolescents with disabilities need to know all this information, but they also may need special preparation concerning sexual abuse and violence and the right to protection from it. It is important to assure that SRH services are friendly to youth with disabilities.”<sup>45</sup>

Encouragingly now, more and more people in the Disability Rights movement as well as those working on sexuality are articulating the need to address sexuality related concerns of people with disabilities. In the course of developing this paper, TARSHI contacted parents, teachers, and other care providers of people with different types of disabilities as well as people with physical disabilities and disability rights activists from different parts of India, and drew upon secondary research to examine existing laws and policies, critiques and analyses regarding sexuality and reproductive health concerns of people with disabilities. This section draws on responses from various stakeholders and key informants (please see the Appendix for the questionnaires and the list of respondents).

Reflecting on her own experience as a woman with a disability, Anita Ghai strongly feels that “There is a need to educate people about sexuality being a basic need, though it’s always been regarded as a constructed need for people with disabilities. Sexuality education

<sup>44</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women’s Health Training Research and Advocacy Cell, M. S. University, Baroda, Vadodara.

<sup>45</sup> WHO/UNFPA. 2009. Promoting Sexual and Reproductive Health for People with Disabilities.

cannot become a reality unless the attitudes and perception of non-disabled people is worked upon". She also believes that we need to be open "and look beyond the socially constructed understanding of sex and sexuality strictly only within marriage."

Javed Abidi says that it is very important to raise the issue of sexuality concerns of people with disabilities. Sexuality is one area which has not been explored enough or talked about in the context of disability in India. He feels that loneliness and the lack of access to both information and spaces for interaction with other people is one of the main obstacles for people with disabilities.

"I strongly feel that there is an immediate need to talk about/address issue of sexuality and/or sexual and reproductive health for people with disabilities because to be human is to be sexual. People with physical disabilities in our society are often regarded as non-sexual adults. If we accept that sexual expression is a natural and important part of human life, then perceptions that deny sexuality for disabled people deny a basic right of expression...." asserts Dr. Balaiah Donta from the National Institute for Research in Reproductive Health.

Geeta Chaturvedi from Khushboo Welfare Society asserts, "The need (to talk/ address issues of sexuality) is immense. Not with persons with disabilities alone but with their significant others as well. Many times it is they who need to understand and break barriers of their own perspectives. Sexuality is an important element in self-respect. This is often missed out in the training of professionals and care providers of people with intellectual disabilities or with cerebral palsy." This lack of attention to issues of sexuality in the training of care providers manifests as discomfort and inappropriate responses when they are forced to confront the sexuality of those in their care.

People with disabilities are often chastised by their care-givers for expressing their sexuality and are often ridiculed as well. Shampa Sengupta recounts that she has seen special educators treat young people's sexual desire negatively; these desires are often the subject of school gossip and often also lead to young people with disabilities

being sexually harassed and even abused. Shampa adds that young people with disabilities are often ridiculed for expressing a desire to become parents or to get pregnant.

According to Shalini Khanna, Director of the Centre for Blind Women, National Association for the Blind, “Adult blind women have a burning issue of sexuality to be addressed as they feel hesitant in expressing their right to sexual freedom and pleasure. Sexual diseases/ ailments are another important area”. Sexual and reproductive health is an important though neglected area that needs to be addressed.

Deepti Nair, an activist from the Deaf Way Foundation, an organisation working on the empowerment of people with hearing and speech impairment in different parts of India, states, “There are so many avenues to get information but the deaf are not aware of them. So the need to educate them is extremely important else they can be sexually abused by people who would take advantage of their disability and ignorance.”

In most of the discussions around the issues of sexuality and disability, we see two strands emerging – health or medical and protection from abuse. The health perspective looks at sexuality from the lens of prevention of infection or of the restoration of sexual functioning (for example, the needs of a heterosexual man who has lost sexual functioning due to an accident or injury). The abuse perspective rightfully considers the vulnerabilities of people with disabilities to sexual abuse at home, in institutions or outside. However, sexuality comprises of more than just these facets.

Actual sexual practices, experiences, adaptive techniques, capabilities rather than ‘disabilities’, also need attention. Women with disabilities, sexual minorities such as lesbian, gay, bisexual, transgender or transsexual people with disabilities, as well as young people with disabilities face discrimination at multiple, intersecting levels. For example, sexual minorities with disabilities are subjected to multiple discriminations on the basis of disability, sexual preference and other aspects of gender and/or race etc.<sup>46</sup>

<sup>46</sup> Sexuality and Disability: A Human Rights Issue. Available at [http://www.disabilityfunders.org/webfm\\_send/59](http://www.disabilityfunders.org/webfm_send/59)

The attention (albeit limited) to only the health or protection from abuse angles, when it comes to sexuality and disability, could be because the dialogue on sexual rights has by and large not included the voices of people with disabilities. Conversely, sexual rights and reproductive rights are generally not a topic of discussion amongst disability groups themselves. As Anita Ghai writes, “The disability movement in India has not fought a single battle which has focused on feminine concerns such as reproductive health and the violation of the basic rights of disabled women. The widespread use of forced hysterectomies of disabled women in government and private institutions all over the country has been ignored by leaders of the disability movement who are essentially middle-class educated men.”<sup>47</sup>

<sup>47</sup> GHAI, A. 2009. The Women’s Movement Must Do More for Disabled Women. InfoChange Agenda. Available at <http://infochangeindia.org/200906017769/Disabilities/Analysis/The-women’s-movement-must-do-more-for-disabled-women.html>

Sexuality and related concerns are often considered by care providers only when they are faced with a ‘problem’ (for example an adolescent with disabilities masturbating in public would cause parents to look for help). The rights of the people with disabilities, their desires for expression and pleasure are neglected. Myths that people with disabilities are asexual or do not need any information on sexuality and sexual health play a significant role in feeding into this. Thus, disability and sexuality has not been addressed from a social justice or human rights perspective and people with disabilities continue to be marginalised and to face discrimination.

### **Are the issues the same for everyone?**

Sexual and reproductive health and sexuality related concerns cut across all sections of society and affect individuals of all backgrounds, religious beliefs, castes, classes and levels of ability. How sexual and reproductive health concerns are manifested and addressed of course depends on where a person is placed on the intersection of these variables. Similarly, it is also true that the experience of disability is mediated by variables of social power, including gender and class amongst others. For instance a man with disability might have better chances of getting educated or married than a woman with disability. Similarly, a person with disabilities belonging to an economically well-placed family might have more access to resources and services than

another person with disabilities who is economically weaker. Where one is placed on multiple axes of power will affect what one is able to access in terms of information, opportunities and services. However, except in the case of people with severe multiple disabilities and/or intellectual disabilities, people with disabilities face many similar challenges and concerns as their non-disabled counterparts. For example, regardless of the disability, in most cases, adolescent girls will menstruate and boys will begin to have emissions. Again regardless of disability, all people need to know how to keep themselves clean and safe from infection and consequences like unwanted pregnancies and have the right to a self-affirming sexuality. Of course, in all cases, this information would have to be tailored to their circumstances, level of comprehension and particular disability.

Do people with disabilities have different sexuality issues as compared to those who are not disabled? Do people with different disabilities face different issues? Or are the issues the same for everyone? The short answer: Yes and No.

According to Renu Addlakha, “Dealing with sexuality among a group of youth with disabilities is no different than among non-disabled youth. The format has to be tailored to compensate for the particular disability, e.g. more audio material for people who are visually challenged, simplicity of language for people with learning difficulties. The challenge, however, lies in helping them understand and accept their sexuality in a social context where their opportunities for sexual expression and guiltless pleasure are extremely limited.”

Renu Khanna, while drawing from the WOHRAC consultative meeting on gender and disability, says, “Most girls I have interviewed with different disabilities are able to manage menstruation with minimum assistance; only those with severe bodily limitations are totally dependant on others.”

Shalini Khanna, who works with people with visual impairment, adds that some students with visual impairments have particular problems related to toilet and menstrual hygiene and cleanliness. This may have

to do with a number of factors including, for example, the fact that they have not been taught this in childhood, or that they are not familiar with changed physical environments when they are out of their homes and do not know how to access toilets or information. Shalini also says “Persistent and continuous observation and counselling are needed.”

Some sexuality issues are the same for all, while some others are different. As Merry Baruah from Action for Autism illustrates, “There are a couple of differences at least with children with autism: one, teaching them the concepts of private and public and how to conduct themselves; and two, helping them gain the actual skills of menstrual management and sometimes of masturbation since this may have to be done in a more autism-specific manner.”

B. Sharada a counsellor and a trainer with the Bangalore-based Parivarthan, a counseling, training and research organisation working to promote positive change in individuals, says that the specific issues that people with disabilities face with regard to sexuality include “Getting into a relationship which is sexual in nature, issues with accessibility and mobility which often leads to isolation and reduces the opportunity to explore or form relationships, low self esteem and body image”.

Seema Chaddha, a Developmental Therapist and Principal Coordinator of the Four Steps School in Delhi, says of her experience with children with intellectual and multiple disabilities, “They have minimum reasoning power and therefore they cannot mould themselves according to a given situation. We have to act together with them in different situations, talk to them and relate to their concerns immediately. There can be no fixed mechanism or a defined method to handle a concern or situation as each child with disability is unique and thus are his or her needs. Each case has to be tackled differently according to the disability, its degree and other considerations.”

No two people experience or express their sexuality in exactly the same way, despite their sharing general commonalities. Different disabilities

may impose certain restrictions and offer other potentialities for sexual expression, depending not only on the nature of the disability but also on the freedoms and restrictions that one's partner, environment and one's own internalised beliefs about sexuality bring to the sexual encounter. Thus, one person may need assistance (with raised pillows, for example) in adopting a particular sexual position while another may discover changing erotic sensitivities on different parts of her body and yet another may need to be taught how to pleasure himself.

# THE POLICY CONTEXT

It is important to look at the policy context to see how and how far people with disabilities are included. Exclusion from public policy is tantamount to exclusion from public life.

Disability has public policy implications in several main areas:

- prevention of disability
- risk management and amelioration by either monetary or in-kind means (when disability can not be prevented)
- the interaction of poverty and disability in a context of widespread poverty and vulnerability
- the interaction of disability with delivery of public services such as education or health in a context where the general systems of service delivery face many challenges.
- the role of public policy in areas like employment and attitudes where the market or social institutions play a dominant role.<sup>48</sup>

<sup>48</sup> BHANUSHALI, K. 2007. Changing Face of Disability Movement: From Charity to Empowerment. Available at <http://ssrn.com/abstract=965999>

Globally, disability policies over the years have evolved from the perspective of prevention and rehabilitation to equalisation of opportunities for people with disabilities. In the 1970s a new era was marked with the human rights approach becoming popular internationally. In 1976, the United Nations General Assembly proclaimed 1981 as the International Year of Disabled Persons. The rights-based approach viewed people with disabilities as equal subjects of law, aiming at empowerment and active participation of people with disabilities in political, economic, social and cultural life in a way that is respectful and accommodating of their differences.

## International Documents on Disability and Rights

Globally, while the issues of education, inclusion and employment had received attention, it was with the adoption by the UN General Assembly of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993 that sexuality concerns of people with disabilities was first raised.<sup>49</sup> Rule No. 9 of the **Standard Rules on Equalization** discusses the right to family life and personal integrity.

It states that “Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.”

The **United Nations Convention on the Rights of People with Disabilities** (UNCRPD) that was adopted in 2006 is a landmark convention which, for the first time in history, talks about the concerns and issues of people with disabilities at a global forum. The convention is unique in the way that it came into force with the active participation of people with disabilities. India is also a signatory to the UNCRPD and therefore has pledged to provide all rights and services as stated in the convention.

Some specific articles from the Convention which can be reviewed from the lens of sexual and reproductive health and rights are given below:

Article 3(a) from General Principles of the Convention mentions ‘respect for the inherent dignity’ of people with disabilities. It is important to treat people with disabilities with dignity and provide them with full and complete information and a supportive environment where they can take their own informed decisions. The issues of bodily integrity vis-à-vis forced sterilisation can be regarded as an example. In other words, forced sterilisation of people with disabilities without their

<sup>49</sup> UNITED NATIONS. 1993. The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. Available at <http://www.un.org/esa/socdev/enable/dissre00.htm>

consent is a violation of their right to bodily integrity. Further, Article 17 also talks about 'Protecting the integrity of the person' ensuring the right to respect for the physical and mental integrity of a person with disabilities on equal basis with others. Article 5, Equality and Non-discrimination, states that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefits of the law.

Article 16 highlights the aspect of Freedom from Exploitation, Violence and Abuse and holds the State responsible to prevent all forms of exploitation, violence and abuse by ensuring State support and assistance to people with disabilities. There have been numerous reported cases of sexual abuse and exploitation of people with disabilities and possibly an equal if not greater number of unreported cases. It is the duty of the State and civil society to educate and sensitise people with disabilities and their care providers about sexual abuse and their vulnerability to it. Services need to be made available for reporting and also for providing help and support to those who face such violence and exploitation. This Article can also be interwoven with Article 5 (Equality and Non-discrimination) to draft laws and policies ensuring and protecting people with disabilities from all forms of abuse, violence and exploitation.

Article 19 of the Convention recognises the equal right of all persons with disabilities to live in the community, with opportunities equal to others, and the State is called upon to take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion. This is a very important right from the perspective of forming a family, getting married or becoming a parent for a person with disabilities. The rights articulated in this Article are also inter-connected with Article 22 which talks about respect for privacy and non-interference in any aspect of personal life. In addition, Article 23 refers to respect for home and family demanding the elimination of all discrimination in matters of marriage, family, parenthood and relationships for people with disabilities. The State is also made responsible for providing accessible age-appropriate information, reproductive and family planning education and the means necessary

to enable people with disabilities to exercise these rights. States need to provide assistance to persons with disabilities in the performance of their child-rearing responsibilities.

Article 25 of the Convention refers to the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability. The provisions made for health are an integral part of wellbeing of an individual. The article specifically mentions accessible services to be provided in the area of sexual and reproductive health.

Article 30 mentions the right to cultural life, recreation, leisure and sports. It is an important right with reference to sexual and reproductive health. Loneliness and isolation caused by structural and attitudinal barriers is one of the main obstacles for people with disabilities to be able to form relationships and friendships with people of a different or same gender. The realisation of the rights in Article 30 would provide a person with disabilities the opportunity to be able to mingle with both non-disabled and disabled people in mainstream society.

## Indian Laws and Policies related to Disability

Even though India is a signatory to the UNCRPD, its provisions are yet to be translated into national laws and policies for people with disabilities. The enactment of the **Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995** is considered a watershed development in the history of the Disability Rights movement in India. However, the Act talks about prevention and rehabilitation with special focus on education and employment for people with disabilities and there is no mention of sexual or reproductive rights of people with disabilities.

Preceding the Persons with Disabilities Act, 1995, two regulations were enacted in India with reference to disabilities. These Acts do not talk in great detail about sexual and reproductive health and rights of people with disabilities and direct provisions for them though they can be expanded to include them. The **Mental Health Act** enacted in 1987 is regarded as the first legal document in the country referring to

<sup>50</sup> The Mental Health Act, 1987. Available at <http://www.disabilityindia.org/mentalact.cfm>

aspects of disability though it focuses on mental illness.<sup>50</sup> The Act was introduced to repeal the Indian Lunacy Act, 1912. The Act looks at mental illness from the perspective of the medical model only and therefore all provisions listed refer to medical practitioners and hospitals and nursing homes. The Act does not make any reference to the sexual and reproductive health and rights concerns of people with disabilities or mental illness. Though if we look at and expand provision number 11, Revocation of License, the Act refers to the wellbeing of the patient saying that if the service provided is 'detrimental to the moral, mental or physical wellbeing of other in-patients, the license can be revoked.' This aspect of 'wellbeing' can possibly be expanded to include issues of sexual and reproductive health and rights.

<sup>51</sup> Rehabilitation Council of India Act, 1992. Available at <http://www.disabilityindia.org/rciact.cfm>

The **Rehabilitation Council Act of India, 1992** is considered to be another important legislation with respect to people with disabilities.<sup>51</sup> The Rehabilitation Council of India runs a number of courses and study programmes related to the rehabilitation of people with disabilities. These courses are nationally recognised. The Act refers to different aspects of operations of the Rehabilitation Council of India, mentioning the provisions for staff, the courses to be run by the Council, etc. A review of the Act shows that there are no provisions from the perspective of sexual and reproductive health and rights or any other social aspects of the lives of people with disabilities.

<sup>52</sup> The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Mental Disabilities Act, 1999. Available at <http://www.disabilityindia.org/trustact.cfm>

The **National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999**, popularly known as the National Trust Act, 1999, was an important legislation as it came after the Persons with Disabilities Act, 1995.<sup>52</sup> The Act mentions constituting a Board which would look into the welfare of people with disabilities throughout the country. The Act aims at empowering people with disabilities to live independently and to participate as fully as possible in the community. It talks about providing support to individuals and their families to ensure care and protection for people with disabilities. The Act has broad provisions related to empowerment and independent living and thus can be expanded to cater to sexual and reproductive health and rights. For example, the health aspects can be expanded to include sexual and

reproductive health services and information. Similarly, participation and belonging to the community can also include rights to form a family and be parents.

Including sexual and reproductive rights of people with disabilities in national laws and policies would be a first step towards acknowledging their sexual and reproductive health and rights, and would need to be accompanied with good implementation strategies as well as structural, systemic and attitudinal changes in society.

## Five Year Plans of the Government of India

The Government of India formulates five year plans to determine its plan of action for development in the country. These plans have a section for people with disabilities and their development. Before the Ninth Five Year Plan (1997-2002) a welfare approach was followed for people with disabilities in the Five Year Plan formulations. In the Ninth Plan, the approach and focus radically shifted to the rights based approach. Two important legislations, the Persons with Disabilities Act, 1995 and the National Trust Act, 1999 further strengthened a rights based approach. The slow pace of implementation of the provisions made in the Ninth Plan led to a reaffirmation of earlier commitments in the Tenth Five Year Plan (2002-2007). Unfortunately, despite two enabling legislations, as well as two Five Year Plans, progress is still slow.

However, a significant achievement during the Tenth Plan has been the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by the Government of India in 2007. It enjoins upon India to ensure that all the rights as enshrined in the Constitution, the current legislations as well as UNCRPD are speedily and effectively operationalised.<sup>53</sup>

## Other laws and policies related to sexual and reproductive health

In India there are other laws and policies that address aspects of sexuality directly and indirectly. They do not directly refer to issues

<sup>53</sup> GOVERNMENT OF INDIA. Eleventh Five Year Plan: What Does it Have for People with Disabilities? Available at [http://punarbhava.in/index.php?option=com\\_content&task=view&id=859&Itemid=658](http://punarbhava.in/index.php?option=com_content&task=view&id=859&Itemid=658)

<sup>54</sup> <http://www.vakilno1.com/bareacts/IndianPenalCode/S377.htm>

<sup>55</sup> The Immoral Traffic (Prevention) Act. 1956. Available at [http://ncpcr.gov.in/Acts/Immoral\\_Traffic\\_Prevention\\_Act\\_\(ITPA\)\\_1956.pdf](http://ncpcr.gov.in/Acts/Immoral_Traffic_Prevention_Act_(ITPA)_1956.pdf)

<sup>56</sup> The Medical Termination of Pregnancy Act. 1971. Available at <http://www.mohfw.nic.in/MTP%20Act%201971.htm>

<sup>57</sup> <http://www.pmfoundation.ws/Documents/FYLLB/Vishaka%20&%20ors.%20V%20State%20of%20Rajasthan%20&%20ors.%20AIR%201997%20SC.htm>

<sup>58</sup> The Act to Protect Women from Domestic Violence Comes into Effect from Today. 2006. Available at <http://www.vakilno1.com/news/Protection-of-Women-From-Domestic-Violence.php>

<sup>59</sup> GOVERNMENT OF INDIA. National Population Policy. 2000. Available at <http://populationcommission.nic.in/npp.htm>

<sup>60</sup> GOVERNMENT OF INDIA. National Health Policy. 2002. Available at <http://www.mohfw.nic.in/np2002.htm>

<sup>61</sup> GOVERNMENT OF INDIA. National Youth Policy. 2003. Rajiv Gandhi National Institute of Youth Development. Available at <http://www.youthportal.gov.in/rightsandresponsibilities.htm>

<sup>62</sup> National AIDS Control Programme Phase III (2006-2011). Available at [http://www.nacoonline.org/upload/Publication/Strategy%20and%20Implementation%20Plan%20-%20NACO%20Programme%20Phase%20III%20\(2006-2011\)%202006.pdf](http://www.nacoonline.org/upload/Publication/Strategy%20and%20Implementation%20Plan%20-%20NACO%20Programme%20Phase%20III%20(2006-2011)%202006.pdf)

of disability. We have listed several below. Although, it is beyond the scope of this paper to delve into and discuss each of them, it would be useful to examine how they might apply to disability.

- Section 377 of The Indian Penal Code, 1860<sup>54</sup>
- Immoral Traffic Prevention Act, 1956<sup>55</sup>
- Medical Termination of Pregnancy (MTP) Act 1971<sup>56</sup>
- Sexual Harassment Guidelines 1997<sup>57</sup>
- The Protection Of Women From Domestic Violence Act 2005<sup>58</sup>
- National Population Policy 2000<sup>59</sup>
- National Health Policy 2002<sup>60</sup>
- National Youth Policy 2003<sup>61</sup>
- National AIDS Prevention Programme Phase III <sup>62</sup>

# GROUND REALITIES

The harsh reality is that there are many challenges to working on disability and sexuality. To begin with, sexuality is not an easy subject to work on. Added to that is the fact that as mentioned earlier, people with disabilities find themselves restricted in society not because of their disability, but because of **societal, structural, systemic** and/or **legal** factors which often do not allow them to participate at par with others. Given that there is a dearth of research in the country, the invisibility of people with disabilities in public spaces and the silence around sexuality, it has been very difficult to learn from people with disabilities themselves about the challenges they face with respect to expressing their sexuality as well as accessing sexuality and sexual and reproductive health information and services.

Parents and care providers of people with disabilities have approached TARSHI for inputs by way of information or sessions and workshops in schools and institutions for children and young adults with disabilities. This usually happens when there have been instances of socially inappropriate behaviour such as masturbation or touching one's genitals in public, or more harmful occurrences such as abuse within the institution. Encouragingly now, more and more institutions are not waiting for an emergency to occur before requesting workshops for teachers and parents to learn how to be more comfortable with the sexuality of those in their care and deal appropriately with these issues.

Privately, and increasingly even publicly, parents, care providers, therapists, special educators and counsellors in different parts of India are acknowledging the need to address sexual and reproductive health and sexuality related concerns of people with disabilities. Some groups of people with disabilities like Friends Organisation in Delhi headed by Dinesh Gupta have a number of young men and women with

disabilities as members some of whom have begun voicing their needs in this area.

Given that there is not much available by way of research into the sexual and reproductive health behaviour and needs of people with disabilities, let us get an idea about the general treatment-seeking scenario for people with disabilities. The 2007 World Bank Report *People with Disabilities in India: From Commitments to Outcomes* reveals that:

- Women with disabilities are around 13% less likely than men with disabilities to seek treatment.
- Higher levels of education of persons with disabilities substantially increase the likelihood of seeking treatment.
- Those with locomotor conditions are the most likely to have sought treatment, while the other extreme is those with hearing and speech disabilities, who are less than half as likely as persons with locomotor conditions to have sought treatment.
- Women with disabilities are even less likely relative to men with disabilities to receive aids and appliances than they are to seek treatment (this may also be because of the low number of women technicians in the health system and the reluctance of women to seek assistance from male technicians).<sup>63</sup>

<sup>63</sup> WORLD BANK REPORT. 2007. People with Disabilities in India: From Commitments to Outcomes. Available at [http://www-wds.worldbank.org/external/default/WDSCContentServer/WDSP/IB/2007/11/21/000310607\\_20071121124147/Rendered/PDF/415850IN0Disab1ort0NOV200701PUBLIC1.pdf](http://www-wds.worldbank.org/external/default/WDSCContentServer/WDSP/IB/2007/11/21/000310607_20071121124147/Rendered/PDF/415850IN0Disab1ort0NOV200701PUBLIC1.pdf)

According to the report, “Those disabled from birth are much less likely to seek care. Secondly, women with disabilities were somewhat less likely to seek care, and even less likely to have assistive appliances. Regionally, access to care appears to be lowest in the North-East and Eastern regions, while those in urban areas throughout India are much

more likely to have sought care. As with the general population, higher levels of education substantially increase the access to health care, as does co-residence of the person with disabilities with their parents.”

The attitudes of service providers also have a significant impact on access to health services by persons with disabilities. Evidence in the World Bank Report indicates that provider attitudes seem to be a constraint for persons with disabilities to access health services. Research from hospitals throughout Orissa found that less than 40% of providers were aware of entitlements under the PWD Act, and that close to 40% of them considered persons with disabilities a burden. In Gujarat, many village health workers did not know that mental illness and mental retardation were disabilities. The evidence of attitudinal barriers was found in surveys conducted in Uttar Pradesh and Tamil Nadu also, which found that 16% of people with disabilities did not seek health services because of provider attitudes. In addition, field research from Karnataka and Rajasthan indicates a generally low level of medical awareness among health care providers of disability issues, in particular with respect to mental health.<sup>64</sup> Unfortunately, in a system that is struggling to respond to overall health issues, disability has little priority.

As the World Bank Report shows, community attitudes continue to be a problem, particularly in the case of mental illness. Such attitudes are in part driven by (and simultaneously reinforce) the lack of rights of persons with disabilities, which may limit their capacity to articulate their need for health services. For some persons with disabilities, communication may itself be an issue, and so they may be additionally constrained by the nature of their disability. In sum, the status of the person with disability within the household, age, type of disability, and time of its onset, can all affect the demand at the individual level.

The statistics above about general health seeking behaviour and how societal attitudes affect this are dismally low. The picture is probably even grimmer when one looks at the sexual and reproductive health seeking behaviour of people with disabilities, and more so women with disabilities. We can conjecture that when the general health seeking

<sup>64</sup> WORLD BANK REPORT. 2007. People with Disabilities in India: From Commitments to Outcomes. Available at [http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607\\_20071121124147/Rendered/PDF/415850IN0Disab1ort0NOV200701PUBLIC1.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2007/11/21/000310607_20071121124147/Rendered/PDF/415850IN0Disab1ort0NOV200701PUBLIC1.pdf)

behaviour of people with disabilities is so low, it must be much lower to the point of being almost non-existent when it comes to sexual and reproductive health seeking. In the case of sexual and reproductive health, the silence and stigma around these issues, further prevents people with disabilities from articulating their need for, let alone, seeking services. Because people with disabilities in India are socialised to be dependent on others for the rest of their lives, it becomes doubly hard for them to independently seek help and services for their sexual and reproductive health concerns in particular.

Let us now look at some specific aspects of sexuality, sexual health and rights and reproductive health and rights.

## SEXUALITY, SEXUAL HEALTH AND RIGHTS

### False assumptions about disability and sexuality

People with disabilities are often assumed to be either ‘asexual’ or ‘oversexed’. Society largely considers them unattractive and therefore incapable of being in sexual or in intimate relationships. People with disabilities are looked upon with pity and considered to be undesirable especially sexually. Societal attitudes which define the individual with disability by his/her disability alone fail to acknowledge the person as a whole. The same understanding further leads to the belief that people with disabilities do not get sexually assaulted or abused as no one will desire them.<sup>65</sup>

<sup>65</sup> KAUFMAN, M, SILVERBERG, C and ODETTE, F (Eds). 2003. The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain and Illness. Powell's Books. San Francisco. Pg 3

At a Kolkata mental hospital, female patients were found naked in the ward on March 8, 2008. The daughter of a woman patient went to visit her mother at Pavlov Mental Hospital, a government-run hospital in Kolkata, West Bengal. As the patient was seriously ill, the doctor took the daughter into the ward to meet her mother. There, they were both shocked to see that all the female patients were stark naked. According to hospital authorities, this was because their clothes had gone for washing. When the doctor protested, one particular hospital staff

member asserted that stripping mentally ill patients of their clothes was “not a serious issue”.<sup>66</sup>

The above case highlights dominant attitudes towards people with disabilities, especially those with mental illness. There are several assumptions at work here: that people with mental illness do not ‘understand’ what is happening to them and so they can be treated in this manner; that people with mental illness are somehow lesser humans and so do not deserve the right to basic human dignity; they are asexual and so it does not matter if they are clothed or not; that they are undesirable to others sexually and so again they do not need to be clothed to be protected from the unwanted attention of others.

Because of a lack of understanding of disability, the assumptions around it are often contradictory. In the words of Merry Baruah, “Interestingly, often it is more the parents and professionals who need to be guided: there is a perception that individuals with disabilities are ‘over-sexed’ and can pose a ‘danger’ to others! On the other hand, they might view the person as a sexless individual with no sexual needs.” People with disabilities are also often regarded to be childlike. Assuming them to be childlike makes people with disabilities even more marginalised as this perception leads to excluding them from information or awareness based programmes on sexual and reproductive health. This assumption also leads to the false belief that all people with disabilities are incapable of engaging in any sexual activity.

C. Mahesh adds, “Due to lack of access and exposure to information and protection, and difficulty with mobility, the bargaining power of persons with disabilities is considerably weak. The priority concerns such as access to education, rehabilitation, livelihood and social security schemes are most often discussed and issues of sexual and reproductive health and rights (SRHR) are hardly discussed. The reason for this negligence towards SRHR issues might be driven by the assumption that people with disabilities are dependent on others and therefore SRHR is not important. Is it the assumption that only when people are functionally and financially independent can they be entitled to SRHR?”

<sup>66</sup> SENGUPTA, S. No Rights for the Mentally Disabled. Available at <http://infochangeindia.org/200804117032/Disabilities/Analysis/No-rights-for-the-mentally-disabled.html>

It is also often wrongly assumed that people with disabilities can never have ‘real’ sex. ‘Real’ sex itself is viewed as penetrative intercourse culminating in an orgasm. The other accompanying assumptions are that sex has to be ‘spontaneous’ and must involve vigorous physical activity. True, some impairments may make spontaneous, vigorous activity difficult, but they do not preclude the possibility of sex. Sexual activities that do not involve penetration or stimulation of the genitals can also be sexually gratifying and pleasurable, but these are often not regarded as ‘real sex’.<sup>67</sup> Sadly, many people with disabilities also buy into this myth. Or worse, believe that sex is not meant for them.

<sup>67</sup> KAUFMAN, M, SILVERBERG, C and ODETTE, F (Eds). 2003. *The Ultimate Guide to Sex and Disability: for All of Us Who Live with Disabilities, Chronic Pain and Illness*. Powell’s Books. San Francisco. Pg 3 - 4

These assumptions lead people to conclude that people with disabilities do not need sexuality education, including information to stay sexually healthy, safe and happy. This is also often the reason for their exclusion from awareness programmes on HIV and AIDS. Praveen from Voluntary Services Organisation says, “It is hard for disabled people particularly – visually impaired, hearing impaired and mentally disabled to have access to information on sexuality”.

Disability rights activist Anita Ghai has come across many examples of professionals like doctors, gynaecologists and other service providers who do not provide relevant information when requested and required. As she puts it, “Professionals like gynaecologists and teachers have a very unfriendly and negative approach towards queries. You need to be married to ask questions related to your sexual and reproductive health. The attitude with which you are given any information is always preceded with the question, why do you need this information at all?”

As the WHO-UNFPA Guidance Note says, “The sexual and reproductive health of persons with disabilities is not a unique, complex, or highly specialized issue. It is, however, an issue that needs more attention and greater creativity, and it needs more attention now. It cannot wait until after other populations or issues are addressed. The inclusion of sexual and reproductive health concerns of persons with disabilities in on-going programmes and policies does not have to be an overwhelming task. It should be an integral part of current work and usually does not need separate or parallel programmes”.<sup>68</sup>

<sup>68</sup> WHO/UNFPA. 2009. *Promoting Sexual and Reproductive Health for People with Disabilities*.

## Body image and self worth

Low self worth and dependence on others could cause people with disabilities to not seek healthcare.

One of the foremost concerns or anxieties that people have about sexuality on the TARSHI helpline has been that of body image concerns especially about shape and size of body parts – “Are my breasts the right shape?”, “Is my penis the right size?”, “Am I attractive?” etc. Such concerns may have greater significance and implications for women and girls as there is a higher premium on beauty for girls in relation to boys.

In 21st century India, and indeed in most parts of the globalised world, sex (and sexuality) is often linked with youth and physical fitness. This is mainly because society’s definition of sexuality is so narrow that some people, such as those with (visible) disabilities, children, and senior citizens, are mistakenly viewed as being incapable of being sexual. With an absence of role models that they can relate to, the concept of what is desirable and attractive and what is not gets deeply internalised by people with disabilities.<sup>69</sup> Messages from family, friends, the media, and society clearly propound the myth of a ‘perfect’ body. These messages compound the belief that people with disabilities are not attractive or ‘complete’. Internalised by people with disabilities themselves, this further leads to a negative body image, low self-esteem and self-confidence and feelings of incompleteness and unworthiness of sex, love, companionship, marriage etc.

Renu Addlakha says, “Adolescents and young people with disabilities must cope with all physical changes, emotional anxieties and social conflicts of able-bodied adolescents, in addition to those produced by their disabilities. Clothing and fashion, music and the media, community activities, social events and school experiences contribute to the development of personal identity at this age. This is a time of learning by watching, doing and rehearsing. Parental values and beliefs are challenged and replaced by peers and the media. These years are full of sexual overtones, messages and activities for those who can

<sup>69</sup> Sexual Health and Disability – Body Image [http://www.sexualhealthtayside.org/Sexual\\_Health\\_and\\_Disability/disability\\_bodyimage.php](http://www.sexualhealthtayside.org/Sexual_Health_and_Disability/disability_bodyimage.php)

<sup>70</sup> ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India. Occasional Paper No.46. Centre for Women's Development Studies, New Delhi.

access them. However, the adolescent with disabilities may be more of a spectator on the sidelines than a participant in this flurry of socio-cultural activity.”<sup>70</sup> It is no wonder then that they are so unprepared for adult relationships of any kind, let alone those that are sexual.

To reiterate, for most adolescents, self identity and image are developed through a mixture of their own ideas, people's perceptions, experimentation, interaction with a peer group and so on. For young adults with disabilities such opportunities of interaction and of building one's own identity and personality are negligible, which further adds to their feelings of unworthiness. Body image and self image are also shaped by the way others treat them or behave with them. People with disabilities often face a lot of stigma and judgment. They are either looked upon with disgust or with pity and embarrassment. In either case, their self respect is damaged and this affects their sexual and reproductive choices. Body image and self esteem are crucial in the context of sexual and reproductive choices. For example, if a young person with a disability has grown up feeling unattractive and unworthy, they may feel very gratified by any positive attention they receive. In such instances, they may readily agree to a relationship or a sexual encounter so that they continue to receive the attention and affection they desire. This could put them at risk of abuse, infection or other unwanted negative occurrences.

Curiosity about issues of sexuality and relationships by a person with disabilities is often considered inappropriate. While non-disabled peers share information and experiences and talk about relationships and sexuality, this is denied to most adolescents with disabilities which further isolates them and adversely affects their body image and self esteem.<sup>71</sup>

<sup>71</sup> Disability and Body Image. Available at <http://www.outsiders.org.uk/leaflets/disability-and-body-image>

Shivjeet Singh Raghav, a Peer Counsellor at the Indian Spinal Injuries Centre shared that spinal injuries can affect a person's mobility as well as their sexual and reproductive organs. This often leads to damaging the individual's body image and thus leads to loss of confidence and desire for sex. The feeling of being undesirable and dependent leads to feelings of isolation. For married people, a spinal injury after marriage

may affect their self esteem to the extent that it leads to breaking long-term marriages.

## Relationships

People with disabilities are often socialised to be dependent and therefore may not have developed skills of thinking independently. Well-intentioned care providers and family members usually treat people with disabilities like children even when they are adults and capable of decision making. This may result in low self-esteem and a lack of confidence in initiating any relationship beyond the scope of care or support. Often people with disabilities grow up believing they do not deserve to be in a relationship as they are not attractive or worthy enough.

Dinesh Gupta from Friends Organisation (a group of people with multiple disabilities) reports that more often than not young adults with disabilities are apprehensive about building relationships. Young men with disabilities shared with TARSHI that when others show any interest towards them, they often feel it is driven by an overriding feeling of pity. Although, these young men also believe that the other person might not always be driven by pity, their lack of confidence in themselves makes them feel so, especially if the other person involved is not disabled. Also, if the relationship fails for any reason, they believe that they were rejected because of their disability. There is always an overriding fear of being used or misled either emotionally or physically.

As mentioned earlier, Javed Abidi from NCPEDP feels that one of the main issues as far as sexual needs and desires of a person with disabilities is concerned stems from loneliness and isolation. The lack of opportunities for interaction, the lack of confidence in oneself and the stigma of being a burden often is a hurdle for people to even explore relationships.

In order to form relationships, people need to be able to meet other people whether in real or virtual spaces. These opportunities are limited for people with disabilities because there are very few accessible

spaces to meet and interact with others. This limitation is due to the inaccessibility of physical spaces like parks, museums, movie halls, bars, restaurants and other leisure spaces, and even work spaces. Added to this are negative attitudes that do not acknowledge the right of people with disabilities to enjoy sexual relationships or even the company of peers in a social setting.

The challenges faced by people with disabilities are exacerbated when their sexual or gender identity does not conform to mainstream society's notions of 'normal'; they then face stigma, discrimination and marginalisation at multiple levels. It is no wonder that those people with disabilities who identify as lesbian, gay, bisexual or transgender (LGBT) are invisible in society. Despite repeated efforts, we were unable to find any information about the experiences of Indian LGBT people with disabilities.

In addition, sexuality is almost always associated with heterosexual marital relationships, negating other relationships like a heterosexual dating relationship or same sex relationships. Consequently, access to information and services is also unavailable to those who fall outside the so-called social norms.

Shalini Khanna mentions, "With blind students same sex behaviour is always an issue especially for hostel staff. As they are unable to see, they don't have any understanding of the body parts of people of the opposite sex, the appearance, till some of them get a chance to touch another's body parts in an affair/ friendship; otherwise all exploration takes place between the same sex because of sharing common spaces. Blind girls in co-ed schools often complain of blind boys trying to feel them and they don't get to know who did it as they can't see. There are many such incidents which take place but are often not reported as even the girls at times enjoy it. Trained and open minded teachers are needed to help these young girls to talk and help them cope and understand their sexuality better."

Merry Baruah says, "... there may be individuals with autism who are transgender, but as it happens with autism they may not express

themselves and therefore we do not have the information. In India very few able independent individuals with autism will speak out because of the stigma of a ‘mental disability’. Hence it would be hard to come by such information.”

## Marriage

Marriage is often the only legitimate space within which sexuality can be played out. Marriage is also often seen as an answer to problems. For example, families of young men with disabilities may look for brides who can then take on the care providing role from the family. According to the WOHRAC report, “In many cases, men with mild mental retardation are married off in the belief that marriage would cure them of their ‘problem.’” In such cases, the practice is to get a beautiful girl with a ‘defect’ for the man with mental disabilities.<sup>72</sup> Similarly non-disabled women from lower socio-economic strata are often married to men with disabilities who belong to a higher socio-economic class. This is often seen as a win-win situation as the poorer family of the woman does not need to worry about dowry for her and the man’s family is satisfied that they have found someone to care for their son with disabilities.

In India, where marriage is traditionally arranged by families, people with disabilities are not considered ‘marriage material’ particularly if they are women. Beliefs about the cause of disability enter the picture when a person’s ‘marriageability’ is considered and when marriage negotiations are undertaken. The fate model of disability is quite popular in India. Needless to say, there are different standards for women and men with disabilities when it comes to their ‘eligibility’ for marriage. If they are considered to be marriageable, they have to undergo the humiliation of being ‘checked out’ by families of prospective spouses and ‘rejected’ time and again. There is also an overriding fear that people (especially women) with disabilities will also produce children with disabilities. However, there seems to be some change in the offing. Popular Indian matrimonial websites like Shaadi.com and Bharat Matrimony have special sections for people with disabilities on their websites.<sup>73,74</sup> Chennai Sai Sankara Matrimonials has a section for

<sup>72</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women’s Health Training Research and Advocacy Cell, M. S. University, Baroda, Vadodara.

<sup>73</sup> Indian Matrimonials, Shaadi.Com. Available at <http://www.shaadi.com>

<sup>74</sup> Indian Matrimonials, Bharat Matrimony. Available at <http://www.bharatmatrimony.com/>

<sup>75</sup> Chennai Sai Sankara Matrimonials. Available at <http://www.ssmatri.com/setup/aboutus.asp>

people with physical disabilities.<sup>75</sup> We do not have information on the success rate of these websites.

The intense distress and anxiety felt by parents and family members when their adult children with mental/intellectual disabilities express a desire to get married is very real. In our interactions with parents and care providers of people with multiple disabilities over the years, this has been one area of concern that has always taken centre stage. “He wants to get married. What do we tell him?” or variations of these questions are often asked.

Renu Addlakha says that parents may find it burdensome to invest effort and time in sending their daughters with disabilities to school or for vocational training. In addition, they may believe that there is no point investing in a disabled girl’s education, as she will never be able to earn in any case. Also because marriage is not seen as a realistic option, families may find it economically unsound to invest in their education or vocational training. Under these circumstances, they may be married to older already married men or men in poor health.<sup>76</sup>

<sup>76</sup> ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India. Occasional Paper No.46. Centre for Women’s Development Studies, New Delhi.

Often, natal families may conceal the fact that their daughter has a disability at the time of the marriage. This is especially so in cases of invisible disabilities like mental illness for example. At other times, married women with disabilities may be ill-treated, abused and even thrown out of their homes for any number of reasons ranging from an inability to satisfactorily perform household duties to bearing a child with disabilities. Annulment of marriage on account of disability is therefore a major factor in the lives of women with disabilities. There are more divorced/separated women than men with disabilities.<sup>77</sup>

<sup>77</sup> ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India. Occasional Paper No.46. Centre for Women’s Development Studies, New Delhi.

Girls and women with disabilities who are seen as asexual and unmarriageable are also not seen as requiring sexuality information. Girls with disabilities are vulnerable to abuse and are therefore over-protected by parents or care providers, which often leads to them being ‘protected’ *from* sexuality related information too; information that could enhance their confidence, sense of control and ability to protect themselves from harmful experiences.

The challenges faced by those who develop a disability later in life are no less difficult. Having lived without a disability for a part of their lives, those who develop disabilities due to accidents, surgery or cancer for example, have to adapt to changed circumstances for themselves as well as deal with how their families and significant others relate to them. Their relationship with their own body may change drastically and it may take a long time for them to come to terms with these changes. Sexually, the fear of not being able to please their partner or not feeling attractive enough for their partner could be a big concern for many people with disabilities, especially women.

## Gender

Traditional notions of disability are characterised by vulnerability, powerlessness and dependence. This is counter to traditional notions of what it means to be a man – aggressive, self reliant and the family bread-winner – and can make it doubly stigmatising for men with disabilities. According to Renu Addlakha, while disability does have negative repercussions on the sexual and gender identities of both men and women, ground realities show that patriarchy does to some extent ease the situation of men with disabilities at least in societies like India. Men with disabilities do have greater access to health, education and employment opportunities than their female counterparts.<sup>78</sup> They also find it easier to find sexual partners, both with and without disabilities. As Renu Khanna says, “Indeed being male shields them from some of the more dehumanising consequences of being disabled that women with disabilities cannot escape. A woman with a disability is considered incapable of fulfilling normative feminine roles of homemaker, wife and mother.” She adds that, “Mothers report difficulties in restraining their mentally challenged sons with regard to masturbation. There are clear gender differences in the way these issues are perceived and managed. Boys’ sexuality is given more space while girls are desexualised from the outset.”<sup>79</sup>

Anita Ghai says, “Disabled women are simply not regarded as women – they are encouraged to be childlike and apologetic towards able-bodied society, which judges them as being better dead than alive.”<sup>80</sup>

<sup>78</sup> ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India. Occasional Paper No.46. Centre for Women’s Development Studies, New Delhi.

<sup>79</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women’s Health Training Research and Advocacy Cell, M. S. University, Baroda, Vadodara.

<sup>80</sup> GHAI, A. 2009. The Women’s Movement Must Do More for Disabled Women. InfoChange Agenda. Available at <http://infochangeindia.org/200906017769/Disabilities/Analysis/The-women’s-movement-must-do-more-for-disabled-women.html>

Kuhu Das from the Association of Women with Disabilities, has been working for many years on empowerment of women with disabilities in the state of West Bengal. She says, “The biggest challenge is the attitude of the women with disabilities themselves, as well as the attitudes of family, community members, and of service providers. There is still a deep-rooted belief that women with disabilities are asexual and therefore no discussion, programme or policy acknowledges or includes their needs.” From where do women with disabilities get the idea that they are asexual? In a culture that is largely silent about women’s sexuality, the voices of women with disabilities with respect to their sexual desires are completely muted. They internalise dominant notions from society from a very young age and feel unattractive, unworthy, unlovable and asexual.

Anita Ghai quotes a woman with cerebral palsy called Disha: “I am forty years old. To date my father has never exchanged a word with me. I have caused loss of his honour. All he does is that he provides financially for me.” Anita adds, “Even though Disha attempts to downplay the impact, her sense of rejection and the pain she experiences is not hard to comprehend.”<sup>81</sup>

<sup>81</sup> GHAI, A. 2003. (Dis) Embodied Form: Issues of Disabled Women. Shakti Books, New Delhi.

Even today, the woman is seen as the repository of the family’s honour in many if not most Indian families. Whether she has a disability or not, the onus of upholding the family’s *izzat* lies with the woman. Parents tend to be over-protective of daughters especially once they attain puberty. This may or may not be so in the case of girls and women with disabilities. Families that believe people with disabilities to be asexual, childlike and/or sexually unattractive may not see the need to protect their daughters with disabilities from unwanted sexual advances. It is often an unconscious belief that is played out as carelessness with respect to looking out for the safety of children and adults with disabilities. On the other hand, parents of girls with disabilities may feel more pressured to ensure the safety of their daughters because they are aware of the vulnerabilities they face. This added pressure can take the form of protectionism, strictness, unwillingness to give their daughters any space/privacy to make friends or be with friends etc.

## Sexuality education

In India, sexuality education is yet to be included in the school curriculum. It is ironic that nearly 60 years since India launched its Family Planning Programme (1952), nearly 40 years since abortion was legalised in the country (1971), nearly 25 years since the first HIV infection was detected in the country (1985) and 15 years after the International Conference on Population and Development (ICPD), there is still silence and confusion about the importance of providing sexuality education to young people. Sexuality education is one of the most debated issues in the country at the moment. Those against introducing sexuality education in schools feel that it will encourage sexual experimentation among young people. Other opponents feel that it would lead to a 'moral decay of our culture'. It is no surprise then that sexuality education for children with disabilities is not being discussed at all.

Sexuality Education is often looked upon with mistrust and fear as it is wrongly considered to be education about sex. A broader concept of **sexuality** (as different from sex) **education** includes educating children and young people about the physical and emotional changes during puberty, consequences of various actions/behaviours and also how to protect themselves from unwanted and harmful consequences of these actions/behaviours.

There are hardly any avenues for people with disabilities to learn about sexuality. Sexuality education is yet to be introduced in the mainstream school curriculum. Many people with disabilities also do not go to school and college. Information related to sexuality becomes even more difficult to access for people with disabilities especially if they are based outside of metropolitan towns and do not have the chance to visit libraries or the Internet. In such cases they are dependent on either their family or institutions (if they are associated with/staying in one) for any information.

Where information on sexuality is imparted, it is largely limited to information on menstrual management and hygiene for girls and about prevention of abuse. Information about safer sex, contraception and

other sexual and reproductive health concerns is not given as it is often thought of as irrelevant for people with disabilities.

Pramada Menon says that whenever the suggestion about introducing sexuality education for people with disabilities is broached in meetings, she finds that people with disabilities in the audience not only agree with the idea but also report feeling validated that their experiences and needs are being acknowledged. According to Deepa Nair, “The main hurdle we face to educate the deaf is that everybody cannot reach out to them and help them. We all need to learn sign language as that’s the only way we can communicate with them. We have to use pictorial strategies and also the help of playing games”. Geeta Chaturvedi recommends that positive stories be created with parents of young adults. This could be done by exploring the option of allowing young adults to use contraception while they are in sexual relationships and helping them lead responsible lives too rather than propagating abstinence alone.

This recommendation might be considered radical by many people as there are also numerous examples of the resistance to talk about sexuality; this is true for people with disabilities and non-disabled people alike. Merry Baruah says, “Family members often feel extremely diffident in discussing anything related to sexuality, regardless of how young the child might be.” Shampa Sengupta recounts, “In one of the sessions during a week-long workshop with young girls with mental disabilities, the topic of body image emerged. So I showed some pictures in the next session – discussed it from the health and hygiene point of view, because I was not sure how the care givers will react. When I went for the next day’s session, the Principal of the school asked me to discontinue with my session. She gave the reason that parents are objecting. However, the same school later approached me for counselling when cases of sexual abuse took place.”

Shashi Paul from Deepalaya declares, “Sexuality education for people with disabilities can play a very important role in their development. It should be imparted from a young age to help them understand and cope with the changes in their mind and body. Currently, the debate

around sexuality education in mainstream schools is a heated issue though we tend to leave out people with disabilities and their need for similar information while discussing these subjects.”

Nithya Balaji from Nalamdana shares, “Creating awareness would be the first step – maybe use mass media. Introduce mainstream characters with disabilities into popular TV shows, not through sob stories but as a part of regular shows. The challenge will also be how to make the gatekeepers realise that sex can also be for the pleasure of it and not necessarily only to procreate!”

According to Kevan Moll’s study, there are a few organisations that are working with children with disabilities that conduct sporadic need-based sessions on issues like HIV that are related to sexuality although there is no set curriculum or source from where these are designed and developed. As different institutions follow their own formats and outlines, there is a lack of consistency in the information given out. Based on his research, Kevan writes “There is a need to provide comprehensive information on sexual health and appropriate behaviour for people with all types of impairments through a holistic sexual health/life skills package, of which HIV is one component.”

There is already an existing pool of resources available on issues like HIV and reproductive health developed by government programmes and NGOs which can be adapted to provide information to people with disabilities. Nithya Balaji’s group Nalamdana was able to provide information and resources on sexuality to a group of about 50 children with different disabilities in a six day workshop in Tamil Nadu. The workshop focused on using different forms of art including theatre, song and mime to show how they faced stigma, their need for understanding and love. Nithya adds, “We also did basic sex and sexuality sessions before they created these mimes, dances and songs. We distributed the Red and Blue books in Tamil to each of them and their teachers. We feel very strongly that such information is every child’s basic right for protection against abuse.”

## Sexual practice

People with disabilities experience sexuality and have similar desires as their non-disabled counterparts. People with disabilities also have the right to explore their sexuality, to be comfortable with their body and different sexual acts and to know and seek what is pleasurable for them. They need information to enable them to experience a self affirming sexuality and have equal rights to access and receive this information. This will empower them to make decisions about their sexual lives from the perspective of both pleasure and safety.<sup>82</sup>

<sup>82</sup> Women, Disabled, Queer. 2008. CREA flier at the AWID Conference, South Africa.

People with disabilities may need assistance in order to do certain things. Being surrounded by one or more care providers means that they have little privacy. Their care providers may not consider that people with disabilities have sexual feelings and desires and may not allow them even the privacy to masturbate.

Physically, muscle weakness, spasms, tremors, contractions or chronic pain may make sexual experiences not so enjoyable. Simple acts of caressing, stroking, stimulation, body movements or physical closeness may be used more creatively by disabled people if other sexual acts are difficult or impossible to engage in due to certain kinds of disabilities. Unfortunately, opportunities to explore their sexuality with their partners are not easily available to people with disabilities.

We did not find much information on how sexual practice is actually affected or can be assisted for people with disabilities in the Indian context. The only detailed information that was available was from the Indian Spinal Injuries Centre. Their initiative to address sexual concerns of people with Spinal Cord Injuries is laudable.

Here are some excerpts from their website:

The disabled are people and people are sexual. Much of our sense of personhood comes from our ability to play a sexual role. The person with disability first obstacle is self de-programming – rejecting the idea that he or she is not a potentially sexual person.

The second is effective militancy – doing something about it. The ideal strategy is open discussion with other individuals or couples who share the same problem and counsel each other. In institutions SIP (Spinal Injury Patients) can be made sexually functional with special counselling and a minimum of physical help. Virtually nobody is too disabled to derive some satisfaction and personal reinforcement from sex.<sup>83</sup>

<sup>83</sup> INDIAN SPINAL INJURIES CENTRE. Sexuality and Sexual Options. Available at [http://isiconline.org/faqs/faq\\_sex.htm](http://isiconline.org/faqs/faq_sex.htm)

The website goes on to give some details on how to deal with erectile problems and the use of certain erection aids and prostheses to assist in sex.

It is interesting to note that most of the information on their website is geared towards men and how they can find sexual pleasure with their women partners.

For women with spinal injuries, the advice is:

For women however the essential sexual functions are unaltered, though there may be a decrease in lubrication of the vagina and they may have little or no sensation on the clitoris. In the case of women, the fertility is not affected by spinal injury, the periods may cease for a while after the injury but they would resume as earlier. They are fertile and thus women should think about contraception if in a sexual relationship.<sup>84</sup>

<sup>84</sup> INDIAN SPINAL INJURIES CENTRE. Sexuality and Sexual Options. Available at [http://isiconline.org/faqs/faq\\_sex.htm](http://isiconline.org/faqs/faq_sex.htm)

People with visible disabilities may have to deal with body image and self esteem issues and this may affect them negatively in a range of ways from an inability to feel sexually attractive and worthy and therefore not find a partner or turn an existing one away to a hesitation to undress completely even with a loving and trusted partner, for example.

## Sexual abuse

People with disabilities are vulnerable to sexual abuse within the family as well as outside (for example, en route to school, in the school

or in a residential institution), more so than non-disabled people. Issues of abuse may be even more complex in their case as they may be dependent on the abuser for their day-to-day needs, physically, psychologically and/or financially.

Children with disabilities are particularly vulnerable to Child Sexual Abuse for a number of reasons including:

- Increased dependence on the family or care-provider for basic care like bathing, dressing, toilet functions so the offender may have increased opportunity for private access to the child with disabilities.
- Limited mobility may result in an inability to escape sexual advances.
- Lack of information about sexuality and the opportunity to develop sexual identity results in confusion and uncertainty over what is acceptable behaviour from other people.
- Limited verbal skills may hinder attempts at disclosing or being understood due to difficulty in communicating.
- Limited options to resist the abuse in the case of residential stay in an institution.

There is very little research available in India on the sexual abuse of people with disabilities. Between 1998 and 2000, the MacArthur Foundation funded a research programme – Project Signpost – to explore deaf adults’ sexual behaviour and vulnerability to HIV involving three groups of deaf people, two schools for deaf children and one workshop of deaf women in Delhi, Mumbai and Chennai. The report *Exploring the Sexual Vulnerability of Urban Deaf Indians* found above average (compared with the general population) levels of sexual abuse of deaf women and children, average levels of sexual activity, and well below average levels of knowledge about the body, anatomy, functions, sexual and reproductive health.<sup>85</sup>

<sup>85</sup> GOPINATH, C. and PATIL, S. 2000. Exploring the Sexual Vulnerability of Urban Deaf Indians. Mumbai

A small 2004 survey in Orissa, India, found that virtually all of the women and girls with disabilities were beaten at home, 25% of women with intellectual disabilities had been raped and six per cent of women with disabilities had been forcibly sterilised.<sup>86</sup>

Parents, husbands and close family members were the most common perpetrators of emotional or physical abuse, for both groups – women with disabilities and women without disabilities. Deaf women were sexually abused by family members and close friends as also were those with intellectual disabilities. Women with physical disabilities appear to be at risk for emotional, physical and sexual abuse to the same extent as women without physical disabilities. Unique vulnerabilities to abuse, experienced by women with disabilities, include social stereotypes of asexuality and passivity, acceptance of abuse as normal behaviour, lack of adaptive equipment, inaccessible home and community environments, increased exposure to medical and institutional settings, dependence on perpetrators for personal assistance and lack of employment options. In order to enable the identification of women with disabilities who are in abusive situations and their referral to appropriate community services, policy changes are needed to increase training for all types of service providers in abuse interventions, improve architectural and attitudinal accessibility to programmes for battered women, increase options for personal assistance, expand the availability of affordable legal services, improve communication among community service providers and, most importantly, provide skill development programmes to make disabled women independent.<sup>87</sup>

The available research reflects that people with disabilities, especially women with disabilities are at high risk of sexual abuse, especially from their care providers.

Given the prevalence of sexual abuse and parents' fears about it, what is being done to prevent it? Unfortunately, parents and care providers sometimes see hysterectomy as a way of protecting girls and women with disabilities from unwanted pregnancy. The focus tends to be on the unwanted consequences of abuse (such as pregnancy) rather than on the abuse itself and finding ways preventing it. This is also perhaps

<sup>86</sup> UN ENABLE. Factsheet on Persons with Disabilities. Available at <http://www.un.org/disabilities/default.asp?id=18>

<sup>87</sup> MOHAPATRA, S and MOHANTY, M. 2004. Abuse and Activity Limitation: A Study on Domestic Violence Against Disabled Women in Orissa. Oxfam. Bhubaneswar, India'.

<sup>88</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women's Health Training Research and Advocacy Cell, M. S. University, Baroda, Vadodara.

why there is so little attention paid to the sexual abuse of boys and men with disabilities. The issue of hysterectomy will be dealt with in more detail later. More positive strategies like attempts to train disabled girls in self-defense, though important, are rarely thought of.<sup>88</sup>

People with mental illness may not identify as persons with disabilities; indeed, they may go through months and even years without any disabling mental condition. Alternatively, they may be able to function more than satisfactorily in their day-to-day life but require strong medicines to maintain their level of functioning. However, medication for mental illness or to help other conditions may have side effects that can have serious impact on the overall wellbeing of a person including on their sexuality. It has been noted that drugs are often forcibly administered to people even when their negative side-effects are known. This is a form of abuse though it may not be acknowledged as such. Often they are not told about such 'side-effects' by their psychiatrists when the medicines are being prescribed, especially if they are women. Men who are prescribed certain medication for depression may be warned that they may have erectile problems as a side-effect. This is not to decry the usefulness of psychiatric medication, but rather to point to the need to affirm patients' rights by informing and educating them about their medication and giving them alternatives to choose from.

## HIV and AIDS

Although the HIV pandemic has opened up the dialogue on sexuality, people with disabilities have not been included because of several misconceptions. To many people it seems a contradiction to work on the risk of HIV infection with people with disabilities and it is indeed an area filled with myths.

Again, one common misconception is that disabled people are not sexually active and therefore not at risk of being infected. Another, that substance abuse, sexual abuse and violence, homosexuality and bisexuality does not exist among disabled people. These assumptions lead to exclusion from HIV prevention and care services of a large group of individuals that face all known risk factors for HIV at equal to up to

three times greater risk of infection than do non-disabled individuals. These were the findings of a study led by Nora Groce called *Global Survey on HIV/AIDS and Disability* that was conducted by the World Bank and Yale University in 2004.<sup>89</sup> The report of the study is called *HIV/AIDS and Disability: Capturing Hidden Voices*. This study examined the intersecting issues of disability and HIV and AIDS on a global scale and revealed that people with disabilities have not been included by the HIV sector for interventions in spite of them being equally vulnerable to all known risk factors. The lack of information and research on the interlinkages between disability and HIV makes people with disabilities even more vulnerable to HIV. The relationship between disability and HIV and AIDS must be further studied in order to design intervention for effective outreach programmes. The study strongly advocates for the inclusion of people with disabilities in HIV and AIDS programmes. It argues that the numbers might seem small but the services needed by HIV positive people with disabilities are the same as those needed by their non-disabled counterparts. The report makes a strong case for work on both HIV and Disability as issues of human rights and public health. It further highlights the fact that people with disabilities make up 10% of the world population and therefore constitute too substantial a proportion to be ignored or excluded from HIV and AIDS programmes. Not that the sheer numbers of people with disabilities is the only reason that this information should be provided to them; they too have the right to information that will help them make wiser choices just like anyone else.

In 2006 Nora Groce published the *Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts* in which she presents a three-tiered practical approach to including people with disabilities into existing HIV and AIDS programmes. This approach constitutes a continuum of inclusion in and access to HIV and AIDS services that range from:

- 1 Inclusion of individuals with disabilities in general HIV and AIDS outreach efforts at little or no additional expense to currently existing programmes,

<sup>89</sup> GROCE, N.E. 2004. HIV/AIDS and Disability: Capturing Hidden Voices. Yale School of Public Health, New Haven, Connecticut. The World Bank. <http://siteresources.worldbank.org/DISABILITY/Resources/Health-and-Wellness/HIVAIDS.pdf>

- 2 Programmes where minor to moderate modifications can be made to existing services to ensure greater participation of individuals with disability at relatively little expense, to
- 3 Outreach efforts that are targeted to disabled audiences that entail specific allocation of resources. (And it should be noted that even such disability-specific efforts are not exceptionally expensive or resource intensive).<sup>90</sup>

<sup>90</sup> GROCE N. E., TRASI R. and YOUSAFZAI A. 2006. Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts. Yale University. Available at <http://www.aids-freeworld.org/images/stories/theagenda/%2319%20Guidelines%20for%20inclusion.pdf>

<sup>91</sup> MOLL, K. 2007. Too Few to Worry About? Or too Many to Ignore - The Exclusion of People with Disabilities from HIV Programmes in India. Available at <http://www.cbrforum.in/articles/Disability%20and%20HIV%20Final%20Report.pdf>

Building on Nora Groce's work, Kevan Moll's study on HIV and AIDS and disability in the Indian context estimates that according to the current prevalence rate of HIV and AIDS in India given by the National AIDS Control Organisation (NACO) there are 319,000 people with disabilities living with HIV in India. Due to the invisibility of this population only a small number (between 0% and 2%) have access to any intervention programmes.<sup>91</sup> This gap is a result of the failure of the HIV sector to include people with disabilities in existing programmes and at the same time the limited awareness and information being shared on HIV by the disability sector itself. The difficulty of access to infrastructure, resources and information that people with disabilities encounter due to existing attitudinal and environmental barriers can also be considered as another reason for this exclusion.

Thankfully, this is changing, at least in some parts of the world. The Africa Campaign on Disability and HIV and AIDS is a unifying umbrella under which disabled people's organisations, organisations of people living with HIV and AIDS, non-governmental organisations, AIDS services organisations, researchers, activists, and other citizens work collectively to achieve two main objectives:

1. A coordinated response involving persons with disabilities in African countries to achieve inclusive national HIV and AIDS policies and programmes, and,
2. Equal access for persons with disabilities in Africa to information and services on HIV and AIDS.<sup>92</sup>

<sup>92</sup> Disability and HIV & AIDS. Available at <http://www.africacampaign.info/about-us/index.html>

AIDS-Free World is an international advocacy organisation that works to promote more urgent and effective global responses to HIV and AIDS. One of the specific areas of their advocacy is Disability and HIV and AIDS. In addition to showcasing the latest advocacy campaigns, there is an excellent resource section on disability and HIV and AIDS on their website.<sup>93</sup>

In India, too, Kevan Moll found that there are some efforts being made to provide HIV prevention services to people with disabilities, primarily among people who are visually or hearing impaired through organisations such as Netrajothi in Chennai and Deaf Way in Delhi. Moll's report gives details of these programmes that he rightly likens to 'beacons' that others can follow.

On the policy front, in April 2009, the United Nations, World Health Organisation and the UNAIDS issued a Policy Brief on Disability and HIV to discuss the actions needed to increase the participation of persons with disabilities in the HIV response and ensure they have access to HIV services which are both tailored to their diverse needs and equal to the services available to others in the community.<sup>94</sup>

There is a need for more research studies on how HIV may affect people with disabilities, their knowledge and awareness of HIV and measures of preventing the transmission of infection either through consensual or non-consensual sexual relationships in order to convert the rhetoric of policies into meaningful action. Some people with HIV may also develop disabilities such as loss of vision or hearing due to opportunistic infections. This is another reason why it is important to look at the links between disability and HIV and AIDS.

<sup>93</sup> Disability and HIV/AIDS. AIDS Free World Available at <http://www.aids-freeeworld.org/content/blogcategory/35/66/>

<sup>94</sup> [http://data.unaids.org/pub/Manual/2009/jc1632\\_policy\\_brief\\_disability\\_en.pdf](http://data.unaids.org/pub/Manual/2009/jc1632_policy_brief_disability_en.pdf)

## REPRODUCTIVE HEALTH AND RIGHTS

### Menstruation

Menstruation and menstrual management create a lot of anxiety for women/girls with disabilities. Parents greatly worry about how they will

<sup>95</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women's Health Training Research and Advocacy Cell, M. S. University, Baroda, Vadodara.

cope with menstruation and sexuality when their disabled daughters reach menarche.<sup>95</sup> In India, menstruation is not regarded simply as a biological process but has many myths and cultural taboos associated with it. Menarche is marked by a number of 'coming of age' rituals in many families even today. At the same time, menstruation is regarded as being dirty and polluting and it is quite common for menstruating girls and women to refrain from many day-to-day activities such as washing their hair, eating pickle, worshipping religious idols, and in some deeply traditional joint families, even entering the kitchen! None of these activities have any actual bearing on menstruation but they are all expressly forbidden. Menstruation, in a sense, is regarded as a necessary horror. In most stores, packets of sanitary pads and tampons are discreetly placed in a bag or wrapped up in newspaper before being handed over to a customer.

Parents and care providers look for ways in which menstruation can be managed more easily for girls/women with disabilities. In actuality, the issues and concerns are largely the same as for non-disabled girls and women except for those with severe/ multiple disabilities or intellectual disabilities. Women and girls with multiple or intellectual disabilities may require additional support from care providers to manage menstruation. This may become especially difficult in institutions that do not have adequate number of trained staff to take care of the women and girls with disabilities.

According to Anita Ghai, at times (depending on the disability and the degree) menstruation might be a more painful experience for a woman with disabilities because of chronic pain or spasms related to the disability. She says, "Women with physical disabilities have faced problems using sanitary pads or tampons as these are not designed keeping their needs in mind. In case women with disabilities are traveling or are away from home or even if they are at home they may need someone to help them change their pads. Some independent women with disabilities complain about the lack of disabled-friendly toilets in public spaces which makes it difficult for them to change their sanitary pads while traveling or when out for work."

## Contraception

People with disabilities are regarded as being unable to bear children or rear them well and be good parents. The perception that they are dependent on others for their basic needs leads non-disabled people to assume that people with disabilities will be unable to be responsible parents. Temporary or permanent methods of contraception are often thrust on women with disabilities by well-meaning service providers or care providers for want of enough information and support to be able to deal with the possibility of unwanted conception.

In many cases it has been seen that disability does not affect a woman's fertility as ovulation and menstruation is controlled by hormones and any other physiological or mental dysfunction may not affect it. However, contraceptive choices are limited for women with disabilities for a number of reasons. At times, women with disabilities are on medication which may interfere with contraceptive pills and other hormonal contraceptives. Contraceptive pills may contribute to unacceptably high risk of blood clots or other side-effects. Physical disabilities also might affect the use of condoms in men.<sup>96</sup> Sponges, diaphragms, female condoms and estrogen-containing oral contraceptives may all be inappropriate if a person's mobility is limited. Depending on the specific disabilities and the requirements of women with disabilities, oral contraceptives containing estrogen, a progesterone-only pill, depo-medroxyprogesterone acetate (DMPA), intrauterine device, tubal ligation, or partner's use of a condom or vasectomy may be considered. It must be stressed that not all the options mentioned here are suitable for women with disabilities. Indeed a number of contraceptives like DMPA are actively discouraged because of their adverse side-effects on people without disabilities as well.

Therefore, in addition to the socio-cultural barriers (of silence and shame associated with sexuality) to accessing contraception, people with disabilities face additional barriers to accessing contraception. These barriers include lack of information on contraceptive choices and where they can be accessed, lack of information on how to use them and a dearth of spaces in which to discuss concerns, fears, challenges

<sup>96</sup> Disability and Sexual Issues. Disability Online. Available at [http://www.disability.vic.gov.au/dsonline/dsarticles.nsf/pages/Disability\\_and\\_sexual\\_issues?OpenDocument](http://www.disability.vic.gov.au/dsonline/dsarticles.nsf/pages/Disability_and_sexual_issues?OpenDocument)

and successes with respect to contraception and safer sex. Most often, contraceptives or contraceptive-dispensing services are not designed keeping people with disabilities in mind. These services or products are considered to be ‘not useful’ for or ‘not required’ by people with disabilities based on the assumption of them being asexual.

There have been many debates and controversies in India regarding non-consensual hysterectomies and sterilisations conducted to protect abusers and prevent pregnancies rather than for the benefit of women with disabilities. It cannot be stressed enough that as far as possible any procedure being conducted or any contraceptive being introduced has to be done with the full informed consent of the person with disabilities, or their care providers/legal guardians in the event that they are not in a position to provide informed consent (in the case of severe intellectual disability for example). In cases where the institution is the legal guardian of the woman with disability, more stringent rules need to be put in place so that the decision to administer contraception is always made keeping the highest good of the woman in mind.

## **Pregnancy**

For women with disabilities, a disabling environment might make pregnancy or childbirth a difficult proposition. Women with disabilities can be as fertile as other women. However, people fear that a disabled person’s child may be born with a disability. Also, people with disabilities are usually considered a burden in society – whether physically or financially and their having children is thought of as adding to that burden.

When it comes to wanting to have children, people with disabilities have to contend with the unfriendly attitude and behaviour of health care professionals who provide information and services related to reproductive health. Basic equipment like low examination tables that are disability-friendly are not available in most hospitals; there is no sensitivity amongst medical staff performing genital examinations to the fact that the person may have lost or heightened sensory function.

Challenges to carrying a pregnancy to term include the non-availability of antenatal care for a woman with disability who might require close medical attention and observation throughout her pregnancy and might require a controlled experience of childbirth, such as through a caesarean section.

By and large, women with physical disabilities have similar fertility rates as non-disabled women. Needless to say, this depends on the nature and severity of the disability. If conception is the aim, assisted technologies can also be explored though it must be said that they are expensive and with relatively low success rates to be an option for many.

Physical disabilities caused by severe spinal cord injuries may impact the fertility of a man with disability more than a woman with a similar disability. This may be more due to erectile dysfunction and an inability to ejaculate than due to sperm production being affected. Assistive devices have been developed in order to help men have and/or maintain an erection.

As most of the procedures or services that a pregnant woman with disabilities requires are similar to that of a non-disabled woman, only some adjustments and sensitivity towards the unique concerns of each woman are all that are required to make services accessible to those with disabilities. The first step towards this has to be in people's attitudes about sexuality concerns of those with disabilities. We must recognise the fact that a woman with a disability has equal rights as any other woman to bear and/or rear a child if that is what she wants. Even in countries like Britain with a high awareness of disability rights, Amie Slavin writes of the discrimination she faces as the blind mother of two little girls.<sup>97</sup> She says, "Sometimes, when I tell people about my children in their absence, I sense a moment's pause while they try to decide if it can be true that I have children. There is a drawing back, as though I may be in the grip of psychosis. The pause will end with a querulous countering: 'But you can't see. How can you have kids?' as though I may not be aware that I am blind."

<sup>97</sup> <http://www.guardian.co.uk/lifeandstyle/2009/aug/08/blind-motherhood-disability>

Single women with a disability may have additional problems. Dr. Balaiah Donta from the Mumbai based National Institute for Research in Reproductive Health relates an instance of a single woman with physical disability who became pregnant. People often quizzed her about how she could have sex considering that she was single as well as had a disability. Reflecting on this, the woman said “You see, not only was it immoral to be an unmarried mother, it was doubly immoral to be an unmarried mother and a severely disabled person.”

## Abortion

Upholding the UNCRPD and basic human rights principles, married and unmarried women with disabilities must have access to safe abortion services. There is no statistical data available on the number of women with disabilities who access abortion services in India. As we know, people with disabilities often face stigma and discrimination while accessing any service or information on reproductive and sexual health issues.

Here is an example of how the lack of sensitivity of clinic staff adds to stress and fear around a procedure that is, in any case, anxiety arousing. A woman with a visual disability had been referred to an abortion clinic by the TARSHI helpline on her request. When she went to the clinic, the staff did not explain the procedures to her and just gave her a form that she could not read. She was left waiting on a chair for some time and was then suddenly asked to go to the room where the abortion was to be performed. Without being given verbal instructions and an account of what was about to occur, she was left feeling very vulnerable and scared. The clinic staff needed only to give her some verbal cues about what would happen in the procedure and once in the abortion room explain who was there and describe the surroundings to save this woman the additional stress and anxiety that she was put through.

Doctors and paramedics should be aware that women with disabilities have the right to seek an abortion and therefore there should be no discrimination in the service provided to them. It is important

to sensitise medical and other staff about the needs of people with disabilities as well as contraindications and complications, if any, of conducting abortions for women with disabilities.

The issue of abortion is a highly complex one in India. Abortion has been legally permissible in India since 1971 but many women still believe it to be illegal and seek back-street abortions. Complicating this is also the fact that because of son-preference in this highly patriarchal society, many women undergo sex-selective abortions to abort the foetus once they learn that it is female. Numbers are naturally hard to come by though in 2006 a study in the medical journal *The Lancet* reported that around ten million female foetuses had been aborted in the preceding twenty years in India.<sup>98</sup>

The Prenatal Diagnostic Techniques (Regulation and Prevention of Misuse) Act 1994 or PNDT Act, was enacted to criminalise sex-selective abortions in India. There are a number of challenges related to the implementation of this Act, a discussion of which is beyond the scope of this paper. The relevance of this Act to issues of disability is well articulated by Anita Ghai and Rachna Johri when they say, “A careful reading of it shows that while selection on the grounds of sex is unambiguously banned, there is a positive sanctioning of selection on the basis of disability. Consequently, this results in the legitimisation of one kind of selection, that is, on the basis of disability, while prohibiting it on grounds of sex.”<sup>99</sup> This has the eugenic potential to sanction the elimination of ‘un-fit’ or ‘inferior’ people and must be challenged.

Ghai and Johri go on to say, “When sex selection has evoked so much debate, the issue of selection on grounds of disability is clearly even more contentious. Again, central to this discussion is the difficulty in conceptualising women’s agency. Both the mother of an unwanted daughter and that of a disabled child face tremendous difficulties. To choose to give birth to a child with disability is to challenge dominant social constructions of both motherhood and childhood. If it is possible to argue that the desire to abort a female foetus arises from the conditions of patriarchy, is a similar logic not applicable to disability selection?”

<sup>98</sup> JHA, P., KUMAR, R., VASA, P., DHINGRA, N., THIRUCHELVAM, D., and MOINEDDIN, R. 2006. Low Male-to-Female Sex Ratio of Children Born in India: National Survey of 1.1 Million Households. *The Lancet*, Volume 367, Issue 9506, Pages 211 - 218. [http://www.thelancet.com/journals/lancet/issue/vol367no9506/PIIS0140-6736\(06\)X6176-7](http://www.thelancet.com/journals/lancet/issue/vol367no9506/PIIS0140-6736(06)X6176-7)

<sup>99</sup> GHAI, A. and JOHRI, R. 2008. ‘Prenatal Diagnosis: Where Do We Draw the Line?’. In *Indian Journal of Gender Studies*. Available at <http://ijg.sagepub.com/cgi/content/refs/15/2/291>

Again, with the advent of assisted reproductive technologies (ARTs), as Sandhya Srinivasan points out in the Introduction to *Making Babies: Birth Markets and Assisted Reproductive Technologies in India* (2010), ARTs promise that by eliminating disability, society will be freed of the responsibility of caring for those with different abilities and needs. Another message is that good parents will get tested: only irresponsible parents will allow disabled children to be born.<sup>100</sup>

<sup>100</sup> SANDHYA SRINIVASAN (Editor). 2010. *Making Babies: Birth Markets and Assisted Reproductive Technologies in India*. Zubaan and SAMA-Resource Centre for Women and Health, New Delhi.

Women have the right to seek an abortion. But do women have the right to abort a foetus once they discover that it might be born with a disability? This is a difficult question to answer and it was the subject of a recent furious national debate in India. Niketa Mehta approached the court in 2008 to abort her 26 week old foetus detected with a congenital heart defect.<sup>101</sup> Whereas the court did not grant to her the right to abort because it was beyond the requisite legal duration for abortion in India (up to 20 weeks), people debated the ethics of such an abortion. On the one hand, many disability rights activists feel that it is the right of the foetus with the disability to be born. On the other hand, many people feel that in the case of severe disabilities that might place strains, including emotional and financial ones, on the family, it is up to the woman to decide.<sup>102</sup> In the end, Niketa Mehta had a spontaneous abortion and the matter was resolved for her. Not so for many other women who find themselves at the epicentre of the dilemma – they are faced with pressure from family and society as well as limited financial and structural support from the State.

<sup>101</sup> VENKATESAN, J. 2009. 'Supreme Court Notice to Centre Over Abortion Law' <http://www.thehindu.com/2009/02/15/stories/2009021555161100.htm>

<sup>102</sup> MADHIWALLA N. 2008. The Niketa Mehta Case: Does the Right to Abortion Threaten Disability Rights? *Indian Journal of Medical Ethics*. Available at <http://www.issuesinmedicalethics.org/164ed152.html>

Who then has the right to decide whether a foetus with disability should be born or not? Is it the woman, the family or the State? Is it the nature or perhaps the degree of the disability that helps one make a decision in such a dilemma?

Doctors and other medical professionals are seen as experts with all the answers and their influence in all matters pertaining to the body is immense. Anita Ghai and Rachna Johri say, "The location of the problems as residing within the individual's body perpetuates the image of the disabled person as sick, flawed, afflicted and suffering. Consequently, the medical model sees the availability of reproductive

technologies, such as prenatal diagnosis, as a blessing that may pre-empt and consequently prevent congenital disability... It is important to note that a focus on individual reproductive choice overlooks the underlying assumption of prenatal diagnosis, namely, that only certain kinds of people should be born in this world. The very existence of prenatal tests assumes that parents will want to select against atypical results. Consequently, is there really a notion of free choice in the true sense of the word in decisions related to elimination of disabled foetuses?" They go on to say that medical advice given on the basis of genetic /prenatal testing does not go into details about the nature of disability, its severity, the various implications of bringing up a child with the disability, not all of which are necessarily negative. According to them, "If professionals, such as obstetricians and counsellors, are ethically committed to assisting prospective parents make informed choices, they should also provide detailed and reliable information about what life is like with a disabling condition, so that their clients can imagine the ways in which such a life can be both rewarding and difficult for themselves and their potentially disabled child."<sup>103</sup>

How about when it comes to women with intellectual disabilities? What does informed consent mean in this case? Can women with intellectual disabilities consent to bearing and rearing children or to having an abortion? This issue has also been in the recent national spotlight. A 19 year old intellectually disabled single woman who was living in a state-run orphanage was found to be pregnant after being raped by one of the guards at the orphanage. The matter of her abortion was taken to the High Court of Punjab and Haryana, motivated by fears that she would be unable to take care of herself and the child, even though she was physically fit to carry the pregnancy to term and deliver the baby. The Court ordered that she undergo an abortion. The Supreme Court then overturned the High Court's ruling because the young woman did not want an abortion and wanted to carry the pregnancy to term.<sup>104</sup> This ruling has raised mixed responses amongst the disability, health, sexuality and reproductive health communities. Those who hailed the judgment pointed out that it recognised the 'legal capacity' of a person with an intellectual disability, while those who are furious with it point out that the young woman will carry to term a pregnancy conceived by

<sup>103</sup> GHAI, A. and JOHRI, R. 2008. Prenatal Diagnosis: Where Do We Draw the Line? In Indian Journal of Gender Studies. Available at <http://ijg.sagepub.com/cgi/content/refs/15/2/291>

<sup>104</sup> THE TIMES OF INDIA. SC Says No to Termination of Victim's Pregnancy. July 22, 2009. Available at <http://timesofindia.indiatimes.com/articleshow/msid-4804983,prtpage-1.cms>

rape and has been offered no support in recognising the implications of pregnancy and motherhood. Needless to say, all the furore has been about the proposed abortion and not about the fact that custodial rape occurs in state-run institutions that are meant to care for their residents and not to sexually exploit them. A more balanced view takes into account all the complex nuances that emerge at the intersection of disability, medical ethics and reproductive rights.<sup>105</sup>

<sup>105</sup> CHOPRA J. 2009. Contested Motherhood. *The Hindu*. August 30, 2009. Available at <http://www.hindu.com/mag/2009/08/30/stories/2009083050180400.htm>

## Hysterectomy

Hysterectomy is viewed and used as a solution to the ‘problem’ of menstruation and sexual abuse of women with disabilities. As mentioned earlier, parents of disabled girls worry about coping with menstruation and sexuality. When girls reach puberty, parents also seek advice on protection from sexual abuse and consequent unwanted pregnancy. Hysterectomy is often suggested and sought as a solution, especially when parents worry about what will happen after they die.<sup>106</sup>

<sup>106</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women’s Health Training Research and Advocacy Cell, M. S. University, Baroda, Vadodara.

<sup>107</sup> In the Guise of Human Dignity. Fact-finding report. Available at <http://cssh.unipune.ernet.in/HumanRights/07%20STATE%20AND%20GENDER/12.pdf>

<sup>108</sup> KHANNA, R., et al. 2004. Consultative Meet to Design a Perspective Building Workshop on Gender and Disability: Report on the Proceedings. Women’s Health Training Research and Advocacy Cell, M. S. University, Baroda, Vadodara.

In a horrific case, in 1994, 11 hysterectomies were performed on intellectually disabled women between the ages of 13 and 35 years. These women were from the Shirur residential institution near Pune. A fact-finding team found that apparently 18 women had been ‘selected’ for the procedure with the blessings of the Director of the Department of Women, Child and Handicapped Welfare.<sup>107</sup> This incident created a storm and raised important ethical questions about the roles and responsibilities of State authorities, informed consent, motivation and intention behind hysterectomies to name a few. The director of the institution as well as the surgeon performing the hysterectomies advocated it because they claimed that the women could not manage menstrual hygiene and made a “mess”. They also advocated it as a remedy for unwanted pregnancies. As the WOHRAC Report says “It is sometimes seen as better to give young women a hysterectomy as a way of protecting them from pregnancy, than to address ways of protecting them from sexual abuse.”<sup>108</sup>

The reality is that hysterectomy is not a ‘solution’. Menstrual

management is teachable. Shampa Sengupta says, “Just as a child with mental disabilities is taught to take a bath, wear clothes, eat and go about her daily tasks, she needs to be taught how to handle menstruation.” Similarly, women with intellectual disabilities can be taught how to communicate about sexuality and to protect themselves from sexual abuse. Removing their uterus and or their ovaries will not prevent rape, but rather increase their vulnerability to repeated rape by pre-empting its discovery through pregnancy.

Studies show that hysterectomy or the removal of the uterus has negative health implications for women and must be undertaken only after due thought, especially for pre-menopausal women. Hysterectomy in addition to being a major surgery with all the risks associated with such surgeries also removes an organ that plays an important role in informing us that the woman’s body is functioning optimally. It can also lead to diminished sexual response and lack of sexual pleasure.

Some family members as well as care providers feel that hysterectomy could become necessary in cases of women/girls with severe/multiple disabilities when they may not be able to manage menstruation on their own. In such cases it is vital that informed consent be taken. In cases of women with intellectual disabilities, the care providers have to make a decision keeping the women’s best interests in mind. In all circumstances, it is important that the intention behind the intervention be clear and the women’s and girls’ rights to bodily integrity, personal autonomy, dignity and her right to sexual and reproductive health be kept paramount. Women’s rights cannot be sacrificed at the altar of excuses about hygiene or the failure to provide a secure environment where they will be safe from rape.

## **Adoption**

Women with disabilities are often discouraged to become mothers whether in terms of bearing a child or rearing one. There are also unfounded fears about their competence to raise children. Adoption agencies in general also do not encourage adoption by people with disabilities because of stereotypical notions about their incompetence.

Anita Ghai states in her book *(Dis) Embodied Form: Issues of Disabled Women* that adoption is not available as an option to women with disabilities. She quotes the experience of a well-placed professional, Sheila, who wanted to adopt a child. Sheila says “However, the desire to bring forth a child was very strong in me. As a result, I went to an adoption agency. They took one look at my disability and informed me in certain terms that I was ineligible for adopting a child. They would rather have children living without mothers. A disabled mother was not their idea of providing parental love to the orphaned child.”<sup>109</sup>

<sup>109</sup> GHAI, A. 2003. *(Dis) Embodied Form: Issues of Disabled Women*. Shakti Books, New Delhi.

This quote illustrates the attitude society and adoption agencies have towards women with disabilities. The evaluation of the person’s ability or inability to be a good parent is filtered through their disability thus violating a right which is available to all others citizens.

There is no uniform law governing adoption in India and it falls under two legislations. The *Hindu Adoption and Maintenance Act, 1956* whereby any an adult with a sound mind who is a Hindu (also Buddhist, Jain or Sikh) can adopt a child. The *Guardians and Wards Act, 1890* is applicable to people of Muslim, Christian, Parsi or Jewish communities whereby the adoption is restricted to ‘guardianship’. There is no special mention that bars a person with disabilities from adopting a child in India though there is a clause that mentions ‘sound mind’, which can be interpreted to exclude people with intellectual disabilities and mental illness and therefore can be discriminatory.<sup>110</sup>

<sup>110</sup> Adoption Laws. Available at <http://www.indiachildren.com/adoption/laws.htm> and Adoption: Under Hindu, Muslim, Christian and Parsi Law. Available at [http://www.legalserviceindia.com/articles/hmcp\\_adopt.htm](http://www.legalserviceindia.com/articles/hmcp_adopt.htm)

The Central Adoption Resource Agency (CARA) encourages people with disabilities to write in and speak about their specific disability and a decision regarding adoption is taken depending on the nature of the disability and whether or not the person will be able to take care of the child. According to CARA, their primary concern is for the child and so their decision is based on whether both parents have disabilities, the nature of disabilities and whether the primary caretaker of the child can handle the child-rearing responsibilities independently or not.

## SOME POINTERS TO THE WAY AHEAD

The vexing issues and hard-hitting questions raised by the juxtaposing of sexuality and disability demand attention. Merry Baruah, from Action for Autism, in New Delhi, finds that, “The biggest challenges perhaps are social and attitudinal barriers. The reality is that individuals with autism too seek sexual partners, but except in a few instances they have to learn that self-gratification is a better option or probably the only option.”

Pramada Menon poses questions: “How do we help people with severe disabilities or disabilities like cerebral palsy? As a community can we provide support for someone who wants to masturbate but cannot do it themselves? Are there ethical concerns about the care providers masturbating the person? If someone with spinal cord injuries wants to have sexual intercourse, how do we organise that? Does one get sex workers to work with these men and women? How receptive would the sex workers be and/or the people themselves or their families? What are the solutions one can look at?” Incidentally, anecdotal evidence suggests that women in prostitution are welcoming of clients with disabilities.

These are questions that many people with disabilities, their parents, care providers and professionals working in the field are already grappling with. Even when people with disabilities do find partners and are ready to get married their families may not be able to support the two of them financially. In a developing country like India where poverty is a reality for the majority of the population, we need to find workable propositions. Anecdotal evidence suggests that parents of people with disabilities are thinking out of the box. For example, several parents of people with disabilities have said that they would only be able to get their disabled son or daughter a spouse who is also disabled and share their care on a rotational basis. So, the couple with

disabilities would live for six months with the woman's family and move to the man's family for the next six months. This would give both sets of families a chance to share the responsibilities rather than, say, the man's family having to look after both their son and daughter-in-law with disabilities.

There are young people with disabilities enquiring about sex toys or sex workers who can be approached for sexual gratification. They are bravely articulating what many others feel and desire.

Admittedly, disability and sexuality are two very complex issues, and in a resource-poor setting like India, working on them may seem like a daunting task. Fortunately, it is heartening to note that work on these issues has already started. Some organisations working on sexuality and sexual and reproductive health and rights are including issues of disabilities in their work. At the same time, organisations working with people with disabilities are recognising the significance of addressing sexuality. These efforts, be they in the form of workshops with parents and care providers, sessions in training programmes for NGOs, panels at conferences, courses on issues of sexuality and disability, or articles, journals and manuals provide examples of what can be done even without large outlays of expenditure. International journals like *Disability and Society* and *Sexuality and Disability* to name a few, regularly publish studies by care providers and professionals discussing their experiences, especially related to issues of sexuality, of working with people with disabilities.<sup>111, 112</sup>

<sup>111</sup> *Disability and Society*. Available at <http://www.tandf.co.uk/journals/carfax/09687599.html>

<sup>112</sup> *Sexuality and Disability*. Available at <http://www.springer.com/psychology/community+environmental+psychology/journal/11195>

The past few years have also witnessed discussions around the recognition of Disability Studies as a separate academic discipline in India. According to Dr. G. N. Karna, Honorary President, Society for Disability and Rehabilitation Studies (SDRS), the development

of Disability Studies as an interdisciplinary academic discipline was granted recognition by the Ministry of Human Resource Development, Government of India in October, 2005. The SDRS played a major role in having this come to pass and has also constituted a Model Curriculum Development Committee on Disability Studies. As things stand today, the Indira Gandhi National Open University (IGNOU) and the Tata Institute of Social Sciences (TISS) have already launched certain academic programmes, including at the Master of Arts (M.A) level, in Disability Studies. The process is underway in other universities as well, including the Alagappa University, Ambedkar University in Delhi, Gauhati University, Periyar University, Pondicherry University, University of Delhi, University of Mumbai, and several universities of Kerala to start programmes of studies in Disability Studies. Moreover, (IGNOU) is also introducing Disability Studies as an optional subject at the Bachelor of Arts (B.A) Level. Currently, the curriculum development for this is underway at IGNOU.

Although most of these courses have only a section or a sub-topic on issues of sexuality and reproductive health and rights, at least some form of Disability Studies appears to be taking root.

In the section below are examples of initiatives that have already begun as well as some suggestions for what can be done.

## Research

Lack of adequate research on disability in India has led to a gap in policy formulation, strategic designing and planning for advocacy and also in planning intervention programmes or services for people with disabilities in India. Research in the field of disability and sexuality will yield a better understanding not just of the concerns and requirements but also the capabilities of people with disabilities. Extensive research is needed on all aspects related to disability and sexuality (sexual and reproductive health, HIV and AIDS, sex work, sexual abuse, same-sex sexual relations, differential needs of people in different disability categories, to name some). The small-scale studies by Renu Addlakha, Kevan Moll, Project Signpost, WOHTRAC, among others, have been

discussed earlier in this paper. More studies, both quantitative and qualitative, are needed.

Given the connections between disability and poverty, it is crucial, especially in a country like India, to examine how different levels of family income differentially affect the lives of people with different disabilities and how level of family income and state benefits interact with the ability to assert sexual and reproductive rights and access to health services and assistive devices. Findings of such research can feed into welfare and social benefit schemes of the government and the design of more appropriate programmes and services.

It is also timely to research the impact and potential of new technologies on the lives of people with disabilities. For example, the Internet and hotlines provide a communication tool where disability is rendered invisible and are used by people with disabilities to build relationships and obtain sexual gratification.<sup>113</sup>

<sup>113</sup> SEYMOUR, W and LUPTON, D. 2004. Holding the Line Online: Exploring Wired Relationships for People with Disabilities. In *Disability and Society*, Vol.19, No. 4.

While designing and conducting research and interpreting results, it is important to keep in mind the sexual rights of people with disabilities and adopt a perspective that is affirmative of people with disabilities and not one that is premised on 'othering' them.

## Skills-building

Parents and care providers face a lot of anxiety and have many questions around issues of sexuality especially when the children with disabilities in their care are growing up. They often try and ignore these concerns as they do not know how to handle them or resolve them. Adolescents with disabilities have similar experiences and requirements as any young person undergoing similar physical and emotions changes. It is of great importance to acknowledge this reality and address these concerns rather continue to be silent around them. There is a pressing need to equip parents and other care providers with information and skills to address sexuality, sexual and reproductive health and rights related issues.

Several organisations already include sessions on menstrual management, genital hygiene and socially appropriate sexual behaviour. The Family Planning Association of India and the Association for the Welfare of Persons with a Mental Handicap in Maharashtra, Mumbai had published a manual called ‘Sexuality and the Mentally Handicapped: A Manual for Parents and Teachers’ in the late 1980s. Renu Addlakha developed a training manual for professionals working with adolescents and young people with physical disabilities called ‘Disability, Sexuality and Reproductive Health in India: A Training Manual for Professionals Working with Adolescents and Young people with Physical Disabilities’ (2005).

According to the WHO-UNFPA Guidance Note, in many communities health workers, social workers, and midwives provide SRH services in people’s homes however, these workers may skip the homes of persons with disabilities, assuming that they do not need services. All those who provide home-based health, nutrition, and social services must be trained and monitored to ensure that persons with disabilities are identified and included in all home-based care and community outreach efforts.<sup>114</sup>

Professionals in the fields of disability and sexuality could come together with parents so that all groups can maximally combine their knowledge, experience and skills and design information packages and training modules on sexuality and reproductive health. Nora Groce’s *Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts* would be a good starting point to map out what interventions can be added on to existing services without any increased expense or with a minimum outlay of costs.<sup>115</sup> Though the guidelines were developed for HIV and AIDS programmes they do not require a leap of imagination to be adapted to other programmes.

## Accessible information and services

People with disabilities require information and services on all aspects of sexual and reproductive health. People with disabilities should be included in all sexual and reproductive health interventions and

<sup>114</sup> WHO/UNFPA. 2009. Promoting Sexual and Reproductive Health for People with Disabilities.

<sup>115</sup> GROCE N. E., TRASI R. and YOUSAFZAI A. 2006. Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts. Yale University. Available at <http://www.aids-freeworld.org/images/stories/theagenda/%2319%20Guidelines%20for%20inclusion.pdf>

awareness programmes, for example HIV and AIDS prevention, reproductive and child health care, access to safe abortions, prevention of violence, etc. It is important to make information available in different formats (large prints, audio versions for example) and at places that are accessible to people with disabilities. Existing services like helplines, counselling centers and other services if sensitised to the requirements of people with disabilities, can without much additional cost include disability issues in their programmes. Midwives should be trained to be aware of specific requirements of women with specific disabilities so that they may be able to offer special skills or information for women with specific disabilities.

With new age technology being developed across the world, many new software programmes and assistive technologies have been introduced for people with disabilities. For example the Digital Accessible Information System, better known as DAISY, is a multimedia synchronization technology standard that allows people with diverse disabilities to access reading material.<sup>116</sup> In addition, the JAWS (an acronym for Job Access with Speech) Screen Reading Software is also being used widely in various institutions for the visually impaired in India. This technology can be used to make information and resources related to sexuality and reproductive health and rights available for people with disabilities in accessible formats.

According to the WHO-UNFPA Guidance Note “Accessibility” also means that resources such as condoms and other commodities are available and provided to persons with disabilities with the same rights to confidentiality, self-determination, and respect that everyone deserves.<sup>117</sup>

Many persons with disabilities in both industrialized and developing countries continue to spend much or all of their lives in nursing homes, group homes or other residential institutions. In such institutional settings persons with disabilities usually do not receive education or information about their reproductive rights. They are often not provided resources such as condoms or other family planning options, nor is testing for HIV or other STIs usually available. Sexual abuse

<sup>116</sup> DAISY: Groundbreaking Technology for the Indian Sector. Available at <http://www.ngopulse.org/press-release/daisy-ground-breaking-technology-disability-sector>

<sup>117</sup> WHO/UNFPA. 2009. Promoting Sexual and Reproductive Health for People with Disabilities.

and violence are common. SRH professionals may need to address these populations specifically to ensure that they receive appropriate services.<sup>118</sup>

Sexuality education should be introduced and encouraged in all schools for children with disabilities across the country. The recently passed Right to Education Act, 2009 is already under amendment for the rights of primary education for children with disabilities.<sup>119</sup> This is an opportunity to lobby for the inclusion of sexuality education for children with disabilities so that sexuality education is incorporated in the new curriculum which is developed around the regulations of the new law.

## Advocacy

A strong network needs to be developed by involving all stakeholders (people with disabilities, parents, care providers, activists, other professionals) to advocate for the sexual and reproductive rights of people with disabilities including those who do not conform to gender and sexuality norms. India is a signatory of the UNCRPD which upholds the rights of people with disabilities and the legal system must recognise the needs and include the rights of people with disabilities like all other citizens in the country. Relevant laws may need to be amended or created to include issues of people with disabilities.

In particular, persons with disabilities, their families, the health and development community, and members of the general public need education about rights and about harmful practices such as forced sterilization, forced abortion, and forced marriage. Furthermore, people need to know whom to contact and where to go to obtain protection against such abuses.<sup>120</sup>

The mass media can play important roles in raising this awareness. SRH professionals, working with people with disabilities, can include information about the SRH of persons with disabilities in mass media outreach efforts and programmes such as the UNFPA and UNAIDS collaborations with MTV (Music Television). Even something as simple

<sup>118</sup> WHO/UNFPA. 2009. Promoting Sexual and Reproductive Health for People with Disabilities.

<sup>119</sup> DISABILITY NEWS and INFORMATION SERVICE. 2009. Final R. T. E. Act to be Amended to Include All Disabilities. Available at [http://www.dnis.org/news.php?issue\\_id=8&volume\\_id=6&news\\_id=915&i=1](http://www.dnis.org/news.php?issue_id=8&volume_id=6&news_id=915&i=1)

<sup>120</sup> WHO/UNFPA. 2009. Promoting Sexual and Reproductive Health for People with Disabilities.

<sup>121</sup> WHO/UNFPA. 2009. Promoting Sexual and Reproductive Health for People with Disabilities.

as including someone with a visible disability among people shown in a poster or TV spot about SRH can help to create a positive image.<sup>121</sup>

There is also a need to actively advocate for the rights of people with disabilities while formulating State policies. If people with disabilities are a part of all planning processes they will articulate their own needs in a manner that is relevant to them, take decisions and formulate plans on their own behalf.

As the WHO/UNFPA Guidance Note says, too often even programmes with the best intentions have treated persons with disabilities as a “target” – passive recipients of services. In fact, persons with disabilities constitute a significant stakeholder group that should have a place at the table whenever health programmes are planned and decisions are made. Their involvement is the best assurance that programmes will meet needs effectively.<sup>122</sup>

<sup>122</sup> WHO/UNFPA. 2009. Promoting Sexual and Reproductive Health for People with Disabilities.

The PWD Act, 1995 is under review for amendment. There is a need to rework the categories or types of disabilities listed. The understanding of disability per se and the issues around it has to be broadened in order to be able to provide better services and information. By restricting categories, we tend to leave out many people with disabilities and marginalise them even further. So far the PWD Act only refers to health in general from a disease prevention perspective, and not one that focuses on optimising health. There are no provisions to do with sexual and reproductive health and rights. The review of the PWD Act is a very good opportunity to push for sexual and reproductive health and rights of people with disabilities and to advocate for ensuring services. Taking from the articles 16, 22 and 23 amongst the many others of the UNCRPD, sexual and reproductive health and rights should be strongly advocated for.

The NCPEDP and the Disability Rights Group, New Delhi along with a number of other organisations and individuals working on disability rights from across the country are also calling for a new consolidated disability law to replace the four existing laws and also to be in consonance with the UNCRPD.

## Social spaces

Social spaces are important for people with disabilities. Difficulties in mobility often lead to isolation of people with disabilities and keep them on the fringe of mainstream society. Common spaces for recreation and interaction are an essential aspect for overall wellbeing of an individual, as well as from the perspective of sexuality. The lack of spaces to socialise with and meet others often leaves people with disabilities lonely and isolated. This also precludes any chances of them forming friendly or intimate relationships.

For this reason, several organisations arrange for people with disabilities to meet. For example, the Deaf Way Foundation conducts Relationship and Health workshops where matters regarding sexuality are openly discussed every month all over India. In the words of a representative of the Deaf Way Foundation, “It is not only an AIDS awareness workshop but we teach all about the human reproductive system.” They also have a Deaf Club where deaf people gather together in church every Sunday. It is a place where they can meet and socialise, make new friends and learn more from each other. Muskaan, an NGO working with adults with disabilities, organises monthly get-togethers like picnics or visits to the market or parks to help people learn skills of social interactions, simple money dealings etc. Similarly, Action for Ability Development and Inclusion (AADI), formerly the Spastics Society Northern India, also organises such outings for children and adolescents at their school.

Organisations can develop programmes for people with disabilities to come together at regular meetings, festivals, cultural and art events as well as include them in other regular ‘mainstream’ programmes. The government has an important role to play here by providing disabled-friendly transport and making commuting accessible for the success of these programmes.

# APPENDIX I

## Questionnaire for Organisations/ Individuals Working with People with Disabilities

- 1 Name and Organisational affiliation (if any)
- 2 In your (individual or organisation) experience and work, do you feel the need to talk about/ address issues of sexuality for people with disabilities? Why or why not? Could you share examples/case studies?
- 3 Considering that sexuality education is important for all, including people with disabilities, what are the challenges you face when introducing sexuality education? Are there positive stories?
- 4 Are there issues related to menstrual management, toilet training or masturbation that you come across with children /young people with disabilities that are different from the non-disabled? If yes, how are they different and how do you address them?
- 5 What are the concerns and challenges you face with regard to disability and sexuality? How do you address them?
- 6 Have you met a person with disability who identifies as transgender? What are their specific issues?
- 7 Have you met a person with disability who identifies as lesbian, gay etc? What are their specific issues?
- 8 Are there any resources or services that you have come across on disability and sexuality?

- 9 Do you conduct/ facilitate or have you heard of any organisations that facilitate trainings / workshops on sexuality for people with disabilities?
- 10 Have you heard of any
  - helplines on sexuality for people with disabilities
  - any social networking sites for people with disabilities
  - marriage bureaus or matrimonial websites
  - general websites addressing sexuality concerns of those with disabilities
  - other resources
- 11 Have you heard of/ read any interesting papers/ documents/ reports which discuss disability and sexuality?
- 12 Have you heard of or read about any courses on disability and sexuality? Do you feel they are needed? What should they focus on?

## **Questionnaire for Organisations/ Individuals Working on Sexuality and Sexual and Reproductive Health**

- 1 Name and Organisational affiliation (if any)
- 2 In your (individual or organisation) experience, do you feel the need to talk about/ address issues of sexuality and/or sexual and reproductive health for people with disabilities? Why or why not? Could you share examples/ case studies?
- 3 Do you incorporate issues of disability in your work on sexuality and SRHR issues? If yes, how?

- 4 What concerns and challenges, if any do you face with regard to disability and sexuality? How do you address them?
- 5 Have you met people of sexual minorities who have a disability? If yes, what are their specific issues? How do you deal with them?
- 6 Have you come across any resources, services, research papers on disability and sexuality? Do specify.
- 7 Do you conduct/ facilitate or have you heard of any organisations that facilitate trainings/ workshops on sexuality for people with disabilities in India or in the South and Southeast Asia region?
- 8 In India or in the South and Southeast Asia region, have you heard of any:
  - Helplines on sexuality and/or for people with disabilities
  - Any social networking sites for people with disabilities
  - Marriage bureaus or matrimonial websites for people with disabilities
  - General websites addressing sexuality concerns of those with disabilities
  - Other resources?
- 9 Have you heard of/ read any interesting papers/ documents/ reports which discuss disability and sexuality?
- 10 Have you heard of/ read about any courses on disability and sexuality in India or in the South and Southeast Asia region? Do you feel they are needed? What should they focus on?

# APPENDIX II

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Prabha Nagaraja, Radhika Chandiramani, and Sameera Shamim conceptualised, researched and wrote this working paper. Gunjan Sharma reviewed several drafts. Arpita Das provided valuable inputs at the beginning.

We are grateful to:

Janet Price, (Honorary Research Fellow at the Liverpool School of Tropical Medicine) United Kingdom, Renu Addlakha (Centre for Women and Development Studies, New Delhi) and Shampa Sengupta (Sruti Disability Rights Centre, Kolkata) for their extensive feedback which helped us strengthen the paper.

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The Astraea Lesbian Foundation for Justice for its support.

TARSHI (Talking About Reproductive and Sexual Health Issues) was founded in 1996 and registered under the Societies Registration Act in 1997.

TARSHI believes that all people have the right to sexual well being and to a self-affirming and enjoyable sexuality. TARSHI works towards expanding sexual and reproductive choices in people's lives in an effort to enable them to enjoy lives of dignity, freedom from fear, infection and reproductive and sexual health problems.

TARSHI runs a phone helpline, conducts trainings and institutes, develops publications, participates in public awareness and education initiatives, and provides technical support to advocacy initiatives. For more information, please visit [www.tarshi.net](http://www.tarshi.net)

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**TARSHI**