

# SEXUALITY AND DISABILITY

in the Indian Context

Working Paper | **TARSHI** 2018



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# SOME ABBREVIATIONS

ARTs	Assisted Reproductive Technologies
CARA	Central Adoption Resource Authority
CESCR	Committee on Economic, Social and Cultural Rights
DAISY	Digital Accessible Information System
DSM	Diagnostic and Statistical Manual of Mental Disorders
ESCAP	UN Economic and Social Commission for Asia and the Pacific
FST	Foundation for Social Transformation enabling North East India
IFFPwD	First International Film Festival for Persons with Disabilities
NCPEPD	National Centre for Promotion of Employment for Disabled People
NFDC	National Films Development Corporation
NIRRH	National Institute for Research in Reproductive Health
NPRD	National Platform for the Rights of the Disabled
POCSO	Protection of Children from Sexual Offences Act, 2012
PwDA	Persons with Disabilities Act 1995
RPD/RPwD	Rights of Persons with Disabilities Act, 2016.
SIDE	South India Disability Evidence [study]
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
TISS	Tata Institute of Social Sciences
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commissioner for Refugees
WHO	World Health Organisation
WID	World Institute on Disability

# EXECUTIVE SUMMARY

This Working Paper is based on the original *Sexuality and Disability in the Indian Context* (2010), which presented the observations, experiences, resources and information sourced from self-advocates, field professionals, and individuals with disabilities and their families. It has been updated to reflect recent changes in law and policy as well as narratives of change shared with us by various sources, some of whom include those who contributed to the 2010 working paper.

During the process of updating this paper we found information on a number of new initiatives, and reviewed many reports and documents that emerged through our desk research, as well as those suggested to us by peers and associates. However, this updated working paper does not incorporate references to all work, research or programmes on sexuality and disability in India. Even as we continued to revisit and revise this paper, there was a sense that more new information and materials exist or are in process, of varying scale and impact. Therefore, this working paper may be read as part of larger, sectoral work-in-progress. We hope it will add value to existing knowledge communication and we request readers to tell us more about materials and initiatives known to them, to add to the growing resource bank in the sector.

Earlier, in 2010, the general approach and prevailing societal attitudes around sexuality and disability mostly pointed to a lack of connection between the two terrains. The reality, however, as many people felt then, and as more people have expressed over the intervening years, is that people with disabilities are also sexual beings with sexual fantasies, feelings and aspirations like anyone else. They are often 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 a continuing lack of personal support as also lack of educational, entertainment, social and health services and rights that are available to other people. The limited conversations on sexuality of people with disabilities have often been held only either from a healthcare perspective or when addressing instances and cases of abuse.

Even now, at first glance, the situation poses enormous challenges, 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. While there is still a dearth of sexual and reproductive health services for people with disabilities, 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. As this paper illustrates, in the last several years there have been more attempts to communicate, and to create offerings, across fields, that foster a greater understanding and acceptance of inclusion. 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 forward the work of affirming the sexual and reproductive rights of people with disabilities.



# INTRODUCTION

*Sexuality and Disability in the Indian Context 2018* revisits the scenario in India vis-a-vis sexuality and disability. It builds on the working paper of the same name that we published in 2010 and incorporates additional information and resources based on interviews with people with disabilities and with parents, teachers, other care providers, field professionals, activists and self-advocates. It also draws upon secondary research to examine existing laws and policies relevant to sexuality and disability in India. This paper lays 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.

There is today an increasingly visible and active engagement with disability and sexuality in India. This engagement has been 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 promising debate on these issues.

There is now a widening cross-section of people working to include issues of disability and inclusion in mainstream conversation and pursuits. In 2012, the TV show *Satyamev Jayate* created by celebrity actor Aamir Khan, aired an episode on Persons with Disabilities which left a strong impact on audiences.<sup>1</sup> In 2015, the First International Film Festival for Persons with Disabilities (IFFPwD) was held in Delhi, an initiative of the Department of

<sup>1</sup> Persons With Disabilities Watch Full Episode. (n.d.). Retrieved from <http://www.satyamevjayate.in/watch-the-episodes/persons-with-disabilities/watch-full-episode-hindi.aspx>

Empowerment of Persons with Disabilities, Ministry of Social Justice & Empowerment, Government of India, in association with the National Films Development Corporation (NFDC).<sup>2</sup> Media focus on this festival helped to publicise it in mainstream media, as well as catalyse discussion around it across other media platforms.<sup>3,4,5</sup> Media people engage in more aware reporting today, sensitive to the approach taken by mainstream players to disability related issues.<sup>6</sup> Yet there remains a dismal lack of support on most fronts for persons with disabilities. For example, the Rio Paralympics 2016 received no media coverage in India until activists took up the issue after which there was some amount of media time given to these games on a daily basis on two channels.

As a result of pressure from cross-sector advocacy and activism, there has also been a slow increase of public, political and judicial focus on the violence, in particular sexual violence, perpetrated on persons with disabilities particularly women and children. However, the connections between disability and sexuality are still not widely, or even correctly identified or articulated. Myths that are demeaning and contribute to human rights violations still persist. There is perhaps also the effect of contending with multiple stigmas, as sexuality and disability both bear the weight of stigma and discomfort. Historically, persons with disabilities have been regarded by society in two contradictory ways – either as non-sexual or as sexually threatening. Largely, 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>7</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>8</sup>

As Renu Addlakha, a social scientist and disability rights researcher at the Centre for Women's Development Studies (CWDS) in New Delhi said, "Sexuality is an area of distress, exclusion and self-doubt for persons with disabilities."<sup>9</sup> Few Indian disability rights activists have been able to raise the difficult issue of sexuality.

2 NATIONAL FILM DEVELOPMENT CORPORATION LIMITED (NFDC). International Film Festival for Persons with Disabilities. 2015. Retrieved from <https://www.nfdcindia.com/IFFPWD/index.html>

3 IANS. (2015, December 25). 'Film fest for disabled people gets signature movie'. *Indian Express*. Retrieved from <http://indianexpress.com/article/entertainment/entertainment-others/film-fest-for-disabled-people-gets-signature-movie/>

4 BOSE, A. (2015, November 30) *IFFPD Signature film* by [Video file]. Retrieved from <https://www.youtube.com/watch?v=AwGroQeYHLg>

5 IFFPD on Facebook. Retrieved from <https://www.facebook.com/1st-International-Film-Festival-For-Persons-With-Disabilities-1097663783596825/?fref=ts>

6 MOKTAN, P. (2016, June 3). Housefull 3 mocks the disabled: Indian Express. Retrieved from <https://www.inshorts.com/news/housefull-3-mocks-the-disabled-indian-express-1464947436173>

7 ALBRECHT, G. L. 2005. *Encyclopaedia of Disability*. University of Chicago. Sage Publications.

8 NISHA. 2006. Regulation of Disabled Women's Sexuality. Retrieved from <http://wwda.org.au/wp-content/uploads/2013/12/nisha1.pdf>

9 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.

The reasons for this are many and complex.

All over the world, there has been, historically, 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. The people who are working on these issues often do so in isolation and may be unaware of other similar initiatives. This is particularly true of India where the sexuality concerns of people with disabilities are rarely acknowledged and therefore have not been considered an important area for study or research, or if they are, have not been widely publicised.

Keeping some of these factors in mind, we asked ourselves: What is the current scenario regarding sexuality and disability in India? What has changed since 2010?

These questions have been answered primarily through desk and internet research focusing primarily on India, as well as conversations, feedback and inputs from organisations and individuals, including self-advocates working in the field of disability and rights. There have been changes in law and policy in India between 2010 and 2017, and we have attempted to include the most significant of these changes and present some observations and comments around them. Organisations and individuals have also undertaken new research as well as new initiatives of varying scope and scale, from global to local, in this intervening period of time. We have been able to identify and include some learning from some of this research as well, though we are aware that one of the limitations of this updating exercise is that we may have missed including other ongoing research and service efforts that could well shed more light on this subject. Even as we were finalising this paper, we were hearing about new initiatives and studies that were being planned or implemented.

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. In 2010, for the purpose of the paper, we had focused mainly on people with physical disabilities. We had acknowledged then, 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. We have 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) and data and research available on people with intellectual disabilities and sexuality in India. Where possible we are including the information we have been able to access through desk reviews and other sources that has emerged over the past six years on some of the work undertaken internationally and in India, on sexuality and issues faced by persons with intellectual disabilities.

For instance, in October 2012, Inclusion International published its Global Report on Article 19: The Right to Live and Be Included in the Community, focussing particularly on persons with intellectual disabilities.<sup>10</sup> This report was two years in the making, with participation from across 95 countries including India, and is based on the stories and experience sharing of self-advocates and their families. The report has articulated three themes that are consistently reflected in the stories of participants: Choice, Support and Inclusion. It states, “In order to live ‘independently’ people with intellectual disabilities need support and need to have relationships with their families and others who enable them to live and be included in the community.” Though it does not have a section focusing specifically on sexuality and inclusion of persons with intellectual disabilities, many portions of the report, particularly the stories and experiences shared by participants, make reference to the desire for marriage and relationships, dating, and starting one’s own family. At the

10 INCLUSION INTERNATIONAL 2012. *Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and Be Included in the Community*. ISBN 978-0-9917430-0-1. ©2012 by Inclusion International. Retrieved from <http://inclusion-international.org/wp-content/uploads/2013/07/Global-Report-Living-Colour-dr2-2.pdf>

same time, issues of safety and vulnerability to violence, including sexual violence are repeated in many of the stories.

In the paper ‘Barriers to Sexuality for Individuals with Intellectual and Developmental Disabilities: A Literature Review’, published in 2015, the authors Sinclair et al. have presented their findings based on a review of 13 articles published between 2000 and 2013 that explored sexuality of individuals with intellectual and/or developmental disability.<sup>11</sup> The paper mentions that though 13 articles were chosen for review on the basis of their match to multiple criteria identified by the researchers, 53 articles on the subject were identified as a result of their search. We are including reference to resources such as these in this paper and continue in our efforts to identify new work in this field, even if it is not in the Indian context.

<sup>11</sup> SINCLAIR, J., UNRUH, D., & LINDSTROM, L. 2015. Barriers to Sexuality for Individuals with Intellectual and Developmental Disabilities: A Literature Review. University of Oregon & Scanlon D., Boston College . *Education and Training in Autism and Developmental Disabilities*, 2015, 50(1), 3–16 © Division on Autism and Developmental Disabilities. Retrieved from [http://daddcec.org/Portals/o/CEC/Autism\\_Disabilities/Research/Publications/Education\\_Training\\_Development\\_Disabilities/Full\\_Journals/ETADD\\_50\(1\)\\_3-16.pdf](http://daddcec.org/Portals/o/CEC/Autism_Disabilities/Research/Publications/Education_Training_Development_Disabilities/Full_Journals/ETADD_50(1)_3-16.pdf)

# 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 still 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, despite increasing efforts and advocacy for policy and legislative provisions to protect and promote sexual rights.

In Indian society, sexuality concerns have been publicly addressed primarily, and often reluctantly, 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. The full scope of sexuality as being vast, and connecting deeply to human life and human rights, at multiple points such as intimacy, relationships, self-expression, self worth, pleasure and eroticism, is just barely being explored. All people have the right to sexual wellbeing, but more often than not,

people with disabilities are regarded not only as non-sexual 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, the World Health Organisation (WHO) offers a working definition of sexuality 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. (WHO, 2006a).<sup>12</sup>

<sup>12</sup> WORLD HEALTH ORGANISATION. Sexual and Reproductive Health. Retrieved from [http://www.who.int/reproductivehealth/topics/sexual\\_health/sh\\_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/)

## Defining Sexual and Reproductive Health and Rights

Sexual and Reproductive Health has been defined by the United Nations Population Fund (UNFPA) as:

a state of complete physical, mental and social wellbeing in all matters relating to the reproductive system. It implies

that people are able to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so.

To maintain one's sexual and reproductive health, people need access to accurate information and the safe, effective, affordable and acceptable contraception method of their choice. They must be informed and empowered to protect themselves from sexually transmitted infections. And when they decide to have children, women must have access to services that can help them have a fit pregnancy, safe delivery and healthy baby.<sup>13</sup>

Reproductive Rights as stated in the Programme of Action of the International Conference on Population and Development in 1994:

embrace certain human rights that are already recognized in national laws, international laws and international human rights documents and other consensus documents. These rights rest on the recognition of the basic rights of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes the right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents.<sup>14</sup>

The WHO defines sexual health as:

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>15</sup>

<sup>13</sup> UNFPA, Sexual and Reproductive Health. Retrieved from <http://www.unfpa.org/sexual-reproductive-health>

<sup>14</sup> UNITED NATIONS POPULATION INFORMATION NETWORK (POPIN). 1994. *Report of the International Conference on Population and Development (ICPD). Programme of Action*, UN Doc. A/CONF.171/13 1994, chap. 7.A. Retrieved from <http://www.un.org/popin/icpd/conference/offeng/poa.html>

<sup>15</sup> WORLD HEALTH ORGANISATION. 2006. *Defining Sexual Health: A Report of a Technical Consultation on Sexual Health, 28-31 January, 2002, Geneva*. Retrieved from [http://www.who.int/reproductivehealth/topics/gender\\_rights/sexual\\_health/en/](http://www.who.int/reproductivehealth/topics/gender_rights/sexual_health/en/)



<sup>16</sup> WORLD HEALTH ORGANISATION. 2010. Developing sexual health programmes. A framework for action. Retrieved from [http://apps.who.int/iris/bitstream/10665/70501/1/WHO\\_RHR\\_HRP\\_10.22\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/70501/1/WHO_RHR_HRP_10.22_eng.pdf)

A 2010 WHO document sets out a guiding framework for sexual health programming.<sup>16</sup> It has identified and listed key sexual health concerns in an annexure. These are related to bodily integrity and to sexual safety, eroticism, gender, sexual orientation, emotional attachment, and reproduction. The list details sub-themes under each of these concern heads. Under bodily integrity and safety, the need for “reduction of sexual consequences of physical or mental disabilities” and of “impact on sexual life of medical and surgical conditions or treatments”, have been articulated. Other significant sub-themes across the listing include, the need for knowledge about the body, as related to sexual response and pleasure, for freedom from exploitative, coercive, violent or manipulative relationships, for skills such as decision-making, communication, assertiveness and negotiation, that enhance personal relationships and to make informed and responsible choices about reproduction. All of this is pertinent to any discussion or reflection on the subject of sexuality and disability.

According to the WHO:

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.

<sup>17</sup> WORLD HEALTH ORGANISATION. 2006. Defining Sexual Health.

The responsible exercise of human rights requires that all persons respect the rights of others.<sup>17</sup>

These rights are not the exclusive domain of any specific group and should be accessible to all; this includes people with disabilities. As Lakshmi Ravikanth of The Banyan, an organisation that works with people with mental illness, says, “That persons with disability (multiple disability) are capable of expressing desire and acting on their sexuality and needs with or without assistance, is the prima facie argument for the rights of PWD (persons with disabilities) in experiencing and expressing their sexuality...”<sup>18</sup>

18 Lakshmi Ravikanth. 2017.  
Personal communication

# UNDERSTANDING DISABILITY

## Models of Disability

Like sexuality, the concept of disability has also evolved over time. It has been viewed from different perspectives over the decades. These also vary, depending on the socio-cultural environment. The different models offer different frames for understanding disability and the consequent approach one takes. In present day India, there is a shift in thinking by and large due to the efforts of disability rights activists, from a welfare/charity approach to a social model and to a rights based approach. However, society at large and perhaps many people with disabilities themselves still need to work on making this shift. But first, let's look at the different models of disability to understand what they are.

**The moral/fate 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. As Deborah Kaplan, Director of the World Institute on Disability (WID), points out in an article on the definition of disability:

The moral model is historically the oldest 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>19</sup>

<sup>19</sup> KAPLAN, D. The Definition of Disability. Available at <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>

Sameera Shamim, who has worked on these issues and is currently pursuing a PhD on Disability and Sexuality at the Tata Institute of Social Sciences (TISS), observes that though the moral model is archaic, it still plays a significant role in the Indian context and in the philosophy of a number of disability organisations even today.<sup>20</sup>

20 Sameera Shamim. 2017. Personal communication

In India, disability is often seen as bad karma. As Renu Addlakha 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>21</sup>

21 ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity.

This is a crucial point that we will come back to later in the paper.

A 2007 World Bank report on disability in India describes the **charity or welfare model** of disability that “views the person with disabilities as the problem and dependent on the sympathy of others to provide assistance.”<sup>22</sup>

22 O'KEEFE, P. 2007. *People with disabilities in India: from commitments to outcomes*. Washington, DC: World Bank. Retrieved from <http://documents.worldbank.org/curated/en/358151468268839622/People-with-disabilities-in-India-from-commitments-to-outcomes>

**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>23</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>24</sup>

23 KAPLAN, D. The Definition of Disability.

24 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.

**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>25</sup>

25 KAPLAN, D. The Definition of Disability.

**The social model** makes a distinction between ‘impairment’ and ‘disability’. Impairment is 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>26</sup> These definitions of impairment and disability have been attributed by various authors such as R Light<sup>27</sup> and R Lang<sup>28</sup> to the Union of the Physically Impaired Against Segregation (UPIAS), an organisation founded in the United Kingdom (UK), in 1972, by disability activist, Paul Hunt.

26 The DEMOS project. 2003. Definitions. Retrieved from <http://jarmin.com/demos/course/awareness/091.html>

27 LIGHT, R. Social Model or Unsociable Muddle? Disability Awareness in Action. Retrieved from <http://www.daa.org.uk/index.php?page=social-model-or-unsociable-muddle>

28 LANG, R. 2001. The Development and Critique of the Social Model of Disability. University of East Anglia. Retrieved from [http://www.ucl.ac.uk/lc-ccr/lccstaff/raymond-lang/DEVELOPMENT\\_AND\\_CRITIQUE\\_OF\\_THE\\_SOCIAL\\_MODEL\\_OF\\_D.pdf](http://www.ucl.ac.uk/lc-ccr/lccstaff/raymond-lang/DEVELOPMENT_AND_CRITIQUE_OF_THE_SOCIAL_MODEL_OF_D.pdf)

29 SHAKESPEARE, T. 2000. Disabled Sexuality: Towards Rights and Recognition. Sexuality and Disability. ISSN: 0146-1044 (Print) 1573-6717 (Online). Available at <https://link.springer.com/journal/11195>

30 O’KEEFE, P. 2007. *People with disabilities in India*.

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 people who are challenging oppressive social norms and structures; they are resisting the exclusion, discrimination and abuse that they have faced from society.<sup>29</sup>

**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>30</sup> According to this model all human beings irrespective of their disabilities have rights, which are unchallengeable. This is in alignment with international human rights laws and instruments that invoke the rights of all human beings, everywhere, to certain

basic, fundamental, freedoms, opportunities and legal protection of these. Therefore this model promotes the dignity, self, entitlement and agency of the individual human being, as a holder of rights, not the recipient of such resources and aid as another may deem fit to apportion out. Importantly, as Bhanushali emphasises in a paper, “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>31</sup>

**The socio-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 speaks of four aspects of disability, “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>32</sup>

Let’s consider, point by point, how each of these four aspects plays out. First, 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.

Second, our bodies are in constant relationship with our environments and most times we provide only for particular types

31 BHANUSHALI, K. 2007. Changing Face of Disability Movement: From Charity to Empowerment. Retrieved from <http://ssrn.com/abstract=965999>

32 GARLAND-THOMSON, R. 2002. Integrating Disability, Transforming Feminist Theory. *National Women’s Studies Association Journal*, 14, (Autumn 2002). The John Hopkins University Press. Retrieved from [https://www.english.upenn.edu/sites/www.english.upenn.edu/files/Garland-Thomson\\_Rosemarie\\_Disability-Feminist-Theory.pdf](https://www.english.upenn.edu/sites/www.english.upenn.edu/files/Garland-Thomson_Rosemarie_Disability-Feminist-Theory.pdf)

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 modalities such as Braille or sign language.

Third, 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 as our body feels, moves, thinks it IS *our self*. That self, that lives through our body, is not stable, however much we may want to think of it that way. 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.

People with disabilities themselves may view disability using any, or many of the models described above, depending upon their social and analytic understanding. 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>33</sup>

<sup>33</sup> KAPLAN, D. The Definition of Disability.

According to Janet Price, a feminist, disability rights campaigner who works on disability, sexuality and social justice mainly in India and the UK, 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, for example, to help men with spinal cord injuries to have erections
- 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>34</sup>

<sup>34</sup> Janet Price. 2009. Personal communication

Janet also points us to the Disability Justice perspective, as framed by Sins Invalid, a performance project that “incubates and celebrates artists with disabilities, centralizing artists of colour and queer and gender-variant artists as communities who have been historically marginalized.”<sup>35</sup>

<sup>35</sup> SINS INVALID. Retrieved from <http://www.sinsinvalid.org/mission.html>

In a 2015 blog post, Patty Berne of Sins Invalid wrote:

A Disability Justice framework understands that all bodies are unique and essential, that all bodies have strengths and needs that must be met. We know that we are powerful not despite the complexities of our bodies, but because of them. We understand that all bodies are caught in these bindings of ability, race, gender, sexuality, class, nation state and imperialism, and that we cannot separate them. These are the positions from where we struggle. We are in a global system that is incompatible with life. There is no way to stop a single gear in motion – we must dismantle this machine.<sup>36</sup>

<sup>36</sup> Ibid.



Berne identifies and articulates ten principles of the Disability Justice framework. The first and primary of these is intersectionality. Each of the ten principles is explained in the post and one of them, the fifth principle, has been described as “a newly articulated contribution to justice-based movements, Recognizing Wholeness, meaning that we value our people as they are, for who they are, and that people have inherent worth outside of commodity relations and capitalist notions of productivity.”

## 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 very 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’, ‘differently abled’, ‘disabled persons’, ‘persons with disability’, and so on, reflecting the politics of the day.

Dr. Anita Ghai, a well-known disability rights activist and academic, says, “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>37</sup>

According to the 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>38</sup>

According to Article 1 of the United Nations Convention on Rights of

37 GHAI, A. 2003. *(Dis) Embodied Form: Issues of Disabled Women*. Shakti Books, New Delhi.

38 WORLD HEALTH ORGANISATION. Disabilities. Retrieved from <http://www.who.int/topics/disabilities/en/>

Persons with Disabilities (UNCRPD)(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.”

This conversation also needs to include developmental disabilities and the concept of neurodiversity. As described on the website of Developmental Services Ontario (DSO), “People with developmental disabilities often require more help to learn, understand or use information than others. This can affect their language and social skills. It may also mean that they need help with daily life as well as other assistance to be as independent and successful as possible.”<sup>39</sup> The concept of neurodiversity adopts a perspective that accepts, and respects neurological differences as part of human variation.<sup>40</sup>

John Elder Robinson, who is an adult on the autism spectrum and also has a son on the autism spectrum, says about neurodiversity:

To me, neurodiversity is the idea that neurological differences like autism and ADHD are the result of normal, natural variation in the human genome. This represents new and fundamentally different way of looking at conditions that were traditionally pathologized; it’s a viewpoint that is not universally accepted though it is increasingly supported by science. That science suggests conditions like autism have a stable prevalence in human society as far back as we can measure. We are realizing that autism, ADHD, and other conditions emerge through a combination of genetic predisposition and environmental interaction; they are not the result of disease or injury.<sup>41</sup>

In India, before the new Rights of Persons with Disabilities (RPD) Act, 2016 was passed by Parliament, the Persons with Disabilities Act (Equal Opportunities, Protection of Rights and Full Participation), 1995, henceforth PwDA 1995, said that “Person with disability means a person suffering from not less than forty per cent of any disability

39 DEVELOPMENT SERVICES ONTARIO. 2016. What Is A Developmental Disability?. Retrieved from <https://www.dsontario.ca/whats-a-developmental-disability>

40 National Symposium on Neurodiversity at Syracuse University. (2011). Retrieved from <https://neurodiversitysymposium.wordpress.com/what-is-neurodiversity/>

41 ROBINSON, J. E. 2013. What is Neurodiversity? Retrieved from <https://www.psychologytoday.com/blog/my-life-aspergers/201310/what-is-neurodiversity>

as certified by a medical authority.” This was criticised as being very limiting and narrow in focus and leaving out a number of conditions from the purview of disability.

Dr. Anita Ghai, commenting on the WHO definition and the one in the 1995 Act, had said, “...they do not reflect the definitions propounded by disabled people themselves. As early as 1976, the UPIAS, expressed a need for an alternative definition of disability.”<sup>42</sup> The UPIAS definitions appear in an earlier section of this paper on the social model of disability.

42 GHAI, A. 2003. (Dis) Embodied Form.

The RPD Act, 2016, became operational on 19<sup>th</sup> April 2017 and has replaced the PwDA 1995. The draft of this legislation had first been introduced in the Rajya Sabha as the Rights of Persons with Disabilities Bill, in 2014. One of the key features of this Act is an increase in the types of disabilities identified, from 7 to 21.

The RPD Act, 2016 defines a person with disability as:

a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others.<sup>43</sup>

43 GOVERNMENT OF INDIA. Rights of Persons with Disabilities Act, 2016. Retrieved from <http://www.disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf>

This definition is in accordance with the UNCRPD.<sup>44</sup> The RPD Act 2016, has extended the effort to define disability by articulating that:

44 UN Convention on the Rights of Persons with Disabilities. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

‘person with benchmark disability’ means a person with not less than forty per cent of a specified disability where specified disability has not been defined in measurable terms and includes a person with disability where specified disability has been defined in measurable terms, as certified by the certifying authority, and,

‘person with disability having high support needs’ means a person with benchmark disability certified under clause (a) of sub-section (2) of section 58 who needs high support.

This provision, Section 58 (2) (a) deals with certifying disability based on assessment of extent of disability as per guidelines that are to be notified by the Central Government.

The RPD Act has been welcomed by many but it also has received its fair share of criticism as we will see in a later section of this paper.

Another recent legislation that is important for us to know about is The Mental Health Care Act, 2017. This Act too, like the RPD Act, states its intention to harmonise the law with the UNCRPD, and replaces the Mental Health Act of 1987. There are intense debates and disagreements on the intent and provisions in the new Mental Health Care Act from multiple sides, as we will see later in this paper.

Shampa Sengupta is a disability rights activist, researcher and academic who has been involved in several policy level interventions and successfully brought in disability related changes in gender-based violence related laws of India. She initiated a non-funded advocacy group called the Sruti Disability Rights Centre and is an Executive Committee member of the National Platform for the Rights of the Disabled (NPRD). Long before the new Mental Health Care Act 2017 was passed, Shampa had stated in an online article in 2008, with regard to defining mental illness or the psychosocial disability that may arise due to a mental health condition:

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 psychosocial 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.<sup>45</sup>

She went on to say that:

Societal attitudes reflect the terms we use. Someone with a psychosocial disability is looked down upon by society. Despite mental illness being included as a category of disability in the

<sup>45</sup> SENGUPTA, S. (2008. April 11). No rights for the mentally disabled. *Infochange India News & Features*. Retrieved from <http://infochangeindia.org/component/content/article/62-disabilities/analysis/7032-no-rights-for-the-mentally-disabled>

46 Ibid.

PwDA 1995, reservations under the law exist only for those who are physically disabled. It is clear that even amongst persons with disability, those with psychosocial 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>46</sup>

The Mental Health Care Act 2017, now defines mental illness thus in Section 2 (1) (s):

a substantial disorder of thinking, mood, perception, orientation or memory that grossly impairs judgment, behaviour, capacity to recognize reality or ability to meet the ordinary demands of life, mental conditions associated with the abuse of alcohol and drugs, but does not include mental retardation which is a condition of arrested or incomplete development of mind of a person, specially characterised by subnormality of intelligence.<sup>47</sup>

47 GOVERNMENT OF INDIA. Mental Health Care Act, 2017. Retrieved from <http://egazette.nic.in/WriteReadData/2017/175248.pdf>

## People with Disabilities in India

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.

Persons with disabilities are devalued because of their perceived 'lack' of capabilities, societal participation and other key aspects of life common in society. As Renu Addlakha says, "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>48</sup>

48 ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity.

Anita Ghai says:

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>49</sup>

49 GHAI, A. 2009. The Women's Movement Must Do More for Disabled Women. *InfoChange Agenda*. Retrieved from <https://disabilitynewsworldwide.wordpress.com/2009/06/24/the-womens-movement-must-do-more-for-disabled-women/>

Referring to the 2007 World Bank Report on 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) may be more stigmatised

50 O'KEEFE, P. 2007. *People with disabilities in India*.

than invisible disabilities (hearing disabilities), thus reflecting a hierarchy of stigma faced by persons with disabilities.<sup>50</sup> However, Janet Price brings in a note of caution saying, “We should be wary of how these hierarchies are understood. Although there may be an apparent hierarchy of attitude, in practice, for example, Deaf and hearing impaired people are consistently reported in research to face excess levels of sexual violence and rape over those with other disabilities and non-disabled people. So practical discrimination is more apparent in sexual terms against people with hearing impairments.”

The World Bank Report also showed how negative societal attitudes also influence the family of persons with disabilities and disabled individuals themselves, leading to low self-esteem and self worth. Based on a recent experience co-editing the July 2017 issue of the *Reproductive Health Matters* journal, Janet points out, “From a western perspective, sexuality is viewed as an individual issue whereas from many of the countries of the South, sexuality is a family/community affair.” In the editorial of the same journal, the editors say:

One major angle for enquiry within the broad spread of heteronormative societies is the ways in which (negative) views of disability affect how the individual's gender and sexuality are perceived. Further, context interacts with the disability-sexuality nexus to alter the individual's experience and ways of becoming. A common view is that disabled people's sexuality is rarely significantly influenced by any factor that is not primarily related to disability. This holds whether it be prejudice and discrimination they face or the effect of the impaired, broken body. This medical perspective neglects other influential factors such as gender, economic status, particularly employment, education and urban-rural residence. In some settings, beyond the individual, it is the family and community that are crucial in offering a route map for the life world including the sexual terrain. The family institution is usually a heteropatriarchal realm of gendered power, organisation

and control, which suffers severe disruption when a disabled person, especially a disabled female, joins it. She forces a re-reading of the values and norms of gender/sexuality, shifting not only the day-to-day material factors but also influential symbolic and cultural norms.<sup>51</sup>

According to Anita Ghai, the popular media also often portrays disability as a 'lack' or 'deficit'. These assumptions, she goes on to say, are rooted in 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>52</sup>

Saying that people with disabilities are 'children of God' is another way of harking back to a charity model. But it appears that this tendency continues even today, in a political context where the use of the word '*divyang*' has been promoted (including by the Prime Minister) since 2015-16 as a result of what has been described as an attempt to change mindsets. The Hindi word *divyang* carries connotations of divinity and divine ability as opposed to the word '*viklang*' which generally means crippled or handicapped or

51 ADDLAKHA, R. PRICE, J. & HEIDARI, S. . 2017. Disability and sexuality: claiming sexual and reproductive rights. *Reproductive Health Matters* Vol. 25 , Issue 50, 2017. Retrieved from <http://tandfonline.com/doi/full/10.1080/09688080.2017.1336375>

52 GHAI, A. 2003. (Dis) Embodied Form.



53 NPRD. 2016. Retrieved from <http://feministlawarchives.pldindia.org/wp-content/uploads/Letter-to-PM-by-National-Platform-for-the-Rights-of-the-Disabled.pdf>

physically challenged. The use of this word and the approach and attitudes that accompany it have caused anger and outrage amongst disability rights advocates and self-advocates. The NPRD addressed a letter of protest, also signed by its affiliate organisations, to the Prime Minister that said<sup>53</sup>:

Even while not questioning the motive behind the coining of this expression, it is needless to say that mere change of terminology is not going to bring about any change in the manner in which people with disabilities are treated. Invoking divinity will in no way lessen the stigma and discrimination that persons with disabilities have been historically subjected to and continue to encounter in their daily lives. Exclusion and marginalisation cannot be addressed by using patronising terms like '*divyang*'. On the contrary, they will only invoke sympathy and underline that charity is what counts.

The letter goes on to say:

Dignity, accommodation and recognition of their rights as equal and productive citizens are what persons with disabilities long for and not any change in nomenclature. We would like to reiterate that disability is not a divine gift. And the use of phrases like '*divyang*' in no way ensures de-stigmatisation or an end to discrimination on grounds of disability. What needs to be addressed are stigma, discrimination and marginalisation that persons with disabilities are subjected to on account of the cultural, social, physical and attitudinal barriers that hinder their effective participation in the country's economic, social and political life.

Attitudinal barriers affect all aspects of life, including the sexual. The attitudinal barriers that disability rights activists fight against also extend to those that are created when it is assumed that people with disabilities are childlike, are unable to make decisions for themselves and are disconnected from sexuality and their own sexual selves. 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.

In a patriarchal society, gender exacerbates women’s experience of disability and societal control over sexuality. Dr. Anubha Rajesh, an early childhood education and disability expert and researcher refers to the report<sup>54</sup> of the UN Secretary General for the seventy second session of the UN General Assembly, observing that “Grave issues have been flagged in ‘Sexual and reproductive health and rights of girls and young women with disabilities’. The report points out that the inability of women to take autonomous decisions exposes them to multiple forms of rights violations, abuse and violence, including forced sterilization and abortion.”<sup>55</sup>

54 UNITED NATIONS. 2017. *Situation of women and girls with disabilities and the Status of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto. Report of the Secretary-General.* Retrieved from [www.un.org/disabilities/documents/gadocs/A\\_72\\_227.doc](http://www.un.org/disabilities/documents/gadocs/A_72_227.doc)

55 Ibid.

Bhargavi Davar, Director of the Bapu Trust for Research on Mind and Discourse, convener of TCI Asia (Trans Asian Alliance on Transforming Communities for Inclusion of Persons with Psychosocial Disabilities) and an Ashoka Fellow, is a well-known mental health activist. In a recent interview, she said:

The key determinant of mental health is gender, within which there are whole new discourses on young people, sexuality, sexual identity, disability identity. Women’s roles in life impact their mental health – for example domestic helpers use their bodies as a way of employment. They express their emotional distress in bodily pain – joint pains, heart palpitations, cold feet – but not through expressed moods or ‘depression’. A lot of their issues are embodied and there may be no vocabulary for psychological pain. Men don’t talk about their bodies in the same way, they turn to alcohol in our working areas.... Research also shows that labeling women as unsound is a way to disempower them legally – whether it is for property or for custody of children. There are no tests for

56 FEMINISM IN INDIA. (2016. November 11). In Conversation With Bhargavi Davar, Mental Health Activist. Retrieved from <http://feminisminindia.com/2016/11/11/interview-bhargavi-davar-mental-health-activist/>

what constitutes an unsound mind and it is all very subjective, based on stereotypes.<sup>56</sup>

Let's also see if numbers help us understand the situation better in the next section.

## Some numbers

While reading this section, it is worth keeping in mind that numbers are only a way of indicating extent; not value. A 'smaller number' does not mean 'lesser rights'.

The new Rights of Persons with Disabilities Act 2016 lists 21 disabilities under six categories:

- (1) Physical disabilities, including locomotor disability, visual impairment, hearing impairment and speech and language disability.
- (2) Intellectual disabilities, including specific learning disabilities and autism spectrum disorder.
- (3) Mental behaviour.
- (4) Disabilities due to chronic neurological conditions and blood disorders.
- (5) Multiple disabilities.
- (6) Any other category which may be notified by the Central Government.

This provides a broader perspective on disability, as opposed to the classification earlier of 7 disabilities within a narrow medical definition of disability, in the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

The 2011 World Report on Disability by the World Health Organisation and World Bank says:

More than a billion people are estimated to live with some form

of disability, or about 15% of the world's population (based on 2010 global population estimates). This is higher than previous World Health Organisation estimates, which date from the 1970s and suggested around 10%.

According to the World Health Survey around 785 million (15.6%) persons 15 years and older live with a disability, while the Global Burden of Disease estimates a figure of around 975 million (19.4%) persons. Of these, the World Health Survey estimates that 110 million people (2.2%) have very significant difficulties in functioning, while the Global Burden of Disease estimates that 190 million (3.8%) have 'severe disability' – the equivalent of disability inferred for conditions such as quadriplegia, severe depression, or blindness. Only the Global Burden of Disease measures childhood disabilities (0–14 years), which is estimated to be 95 million (5.1%) children, of whom 13 million (0.7%) have 'severe disability'.<sup>57</sup>

In the 2011 Census of India information on eight types of disability was collected as it was designed to cover disabilities listed in the PwDA, 1995 and The National Trust Act, 1999. These are the disabilities covered in the census:

- Seeing
- Hearing
- Speech
- Movement
- Mental retardation
- Mental illness
- Any other
- Multiple disabilities

According to this census, the total number of persons with disabilities in India is 26,810,557 that is over 26.8 million, of which 15 million are males and 11.8 million are females<sup>58</sup> (We could find no

57 WORLD HEALTH ORGANISATION and WORLD BANK. 2011. *World report on disability*. Retrieved from [http://apps.who.int/iris/bitstream/10665/70670/1/WHO\\_NMH\\_VIP\\_11.01\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/70670/1/WHO_NMH_VIP_11.01_eng.pdf)

58 CENSUS OF INDIA. 2011. Data on Disability. Retrieved from <http://www.languageinindia.com/jan2014/disabilityinindia2011data.pdf>

record of transgender or intersex people with disabilities). Over 4% of this population is in their 60s, over 6% in their 70s and over 8% in their 80s. The proportion of the disabled population is higher in the senior age groups.

There are challenges to using census data as a basis for studying the situation and circumstances of persons with disabilities. One such challenge is that the census excludes a great proportion of the population that does not fall within the percentage of disability as articulated for the purpose in census criteria. Disability experienced due to chronic or terminal illness, or due to temporary impairment for a significant period of time does not receive focus either.

Any use of a narrow definition of disability implies that many people are excluded from 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.

Now, with the RPD Act of 2016, it is very likely that many more people may be counted in as persons with disabilities, such as those who have survived an acid attack, and persons with specific learning disabilities and Autism Spectrum Disorders. Further, the definitional parameters used for data collection in Census 2011 may not allow a deeper insight into the type of disability covered by the blanket term 'Any other', as well as, perhaps this term did not always cover other categories of disability, such as neurological conditions (Multiple Sclerosis, Parkinson's) or blood disorders (Haemophilia, Thalassemia or Sickle Cell disease), that are now listed separately in the RPD Act.

Disability statistics 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), has written in an article that:

According to the 2011 census, India has about 2.68 crore (over 26 million) people with a disability, that is, 2.21% of the Indian population. On the other hand the conservative estimates of the World Bank and World Health Organisation suggests that there are about 70-100 million individuals with a disability in India. This disparity in the statistics suggests that we do not have any clear numbers, which further means that there is no clarity to the number of individuals that are being excluded from mainstream society.<sup>59</sup>

Further, the enumeration does not include people with mild and moderate disabilities, leaving a large group out of the final statistics.

If there is no consensus on general statistics about the number of people with disabilities in the country, there is even less information about the sexual and reproductive health behaviour and needs of people with disabilities. Given this situation, let us get an idea about the general treatment-seeking scenario for people with disabilities. The 2007 World Bank Report on People with Disabilities in India 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>60</sup>

59 ABIDI, J. (2016. July 31). Here's how people with disabilities in India can get better financial assistance. *The Indian Express*. Retrieved from <http://indianexpress.com/article/blogs/javed-abidi-is-the-global-chair-disabled-peoples-international-and-a-leading-global-light-on-the-subject-2945521/>

60 O'KEEFE, P. 2007. *People with disabilities in India*.

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.<sup>61</sup>

61 Ibid.

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 then Persons with Disability Act (1995) and that close to 40% of them considered persons with disabilities a burden. In Gujarat, village health workers were unable to make the distinction between mental illness and intellectual 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. 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 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. 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.

Janet Price reminds us of another key issue that has been identified in research findings from other countries regarding sexual and reproductive health treatment-seeking amongst women with disabilities: being accompanied by a family member for doctor's visits takes away privacy and is a barrier to discussing issues confidentially.

Let's look at some other parameters that show us whether people with disabilities are integrated in our society. The average literacy and education rates amongst people with disabilities are much lower than those of their non-disabled counterparts. Reports suggest 54% literacy rate among people with disabilities against a 74% average for the general population in India. While there is wide disparity in the literacy rate across men and women, this increases in rural areas. In urban areas, 72% of men with disabilities, as against 61% of women with disabilities are literate. In rural areas, the figures



62 BANSAL, S. 2016. Census 2011 records rise in literacy among disabled. *The Hindu*. Retrieved from <http://www.thehindu.com/news/national/Census-2011-records-rise-in-literacy-among-disabled/article14491381.ece>

63 MAMPATTA, S. 2015. India's missing disabled population. *Live Mint e-Paper*. Retrieved from <http://www.livemint.com/Opinion/1rx8tSYGwHBoZRsvdNFIBP/Indias-missing-disabled-population.html>

64 O'KEEFE, P. 2007. *People with disabilities in India*.

65 UNDP. 2016. *Human Development Report 2016. Human Development for Everyone*. Retrieved from [http://hdr.undp.org/sites/default/files/2016\\_human\\_development\\_report.pdf](http://hdr.undp.org/sites/default/files/2016_human_development_report.pdf)

stand at 58% of men with disabilities who are literate, while only 38% of women with disabilities are literate.<sup>62</sup>

Further with reference to employment prospects of people with disabilities, the scenario is again dismal. By some estimates, over 63% of the disabled population is unemployed.<sup>63</sup> The World Bank Report 2007 reflects that having a disability reduces the probability of being employed. The marginal effect of disability on employment probability is high for men, lower for women and higher for those with more severe disabilities (both men and 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>64</sup>

The UN Human Development Report of 2016 gives India a rank of 131 out of 188 countries surveyed. The report states:

The human development approach has always advocated for the expansion of capabilities and freedoms to the fullest for all people regardless of gender, nationality, ethnicity, sexual orientation or any other group identity. But translating universalism from principle to practice will have to rely on more than mapping the groups that have been bypassed in the human development journey and identifying the barriers to ensure that human development reaches everyone. It will also require refocusing on some elements of the human development analytical approach that have so far been insufficiently considered, such as voice and participation, identity and diversity, inclusion and social justice.<sup>65</sup>

The fact is that any discussion of sexuality and disability is incomplete without also being able to discuss the acute multiple marginalisation of those who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI). However, it is difficult to even find information so disaggregated that a researcher can cross-reference data across disability and sexual identity. We need data disaggregation in a way that it is possible to identify the particular experiences and challenges faced by individuals who are positioned at a meeting point of different kinds of discrimination due to factors such as sexual identity, gender and type of disability. Without the details that this data would present, issues of voice, participation diversity and inclusion become very challenging to articulate.

# PERSPECTIVES ON DISABILITY AND SEXUALITY

## Does Sexuality Matter?

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. This is quite a nascent but very welcome phenomenon as up to several years ago, there was nothing but silence on sexuality and disability. For instance, in 2011, Malini Chib, a disability rights activist and author who has cerebral palsy, wrote in an online article:

The word sex and disability don't go together. Can disabled people have sex? Tauba tauba! A topic best not mentioned. Even though I have been brought up in a westernised, liberated family and social strata – the topic has rarely been brought up with me. Most people think that if they start the conversation, they will hurt my feelings. Why does the topic sex frighten everyone when it comes to disabled people?<sup>66</sup>

66 CHIB, M. (2011. November 3). I'm single because of my body. *Mumbai Mirror*. Retrieved from <http://timesofindia.indiatimes.com/life-style/relationships/love-sex/Im-single-because-of-my-body/articleshow/10051306.cms?>

It is extremely difficult to find records of a public communication or public conversations on disability and sexuality initiated by or involving the participation of, women with disabilities in India. In the article Malini goes on to say:

There has been a lot of progress, worldwide, in the last 50 years in the area of disability rights and our visibility, access, etc. Activists, including disabled activists, continue to do a marvellous job in advocating equal rights for the disabled. But even in the West, which is far more advanced in terms of access and facilities – sexuality is still a taboo. In India, due to the enormity of the barriers surrounding sexual relationships, disabled people often find it easier to deny their desires. This

denial of sexual identity implies that looking for a partner or acknowledging sexuality may make disabled women, in particular, susceptible to being branded 'crude' or 'sex-mad'. We are looked at askance for even dreaming of something so scandalous! Disabled men are not as discriminated on this front as much. They still manage to get able-bodied partners. Perhaps because for the most part, in a heterosexual relationship, it is the women who act as nurturers or caretakers – glorified mummies!<sup>67</sup>

67 Ibid.

What Malini is saying from personal experience was also found by Renu Addlakha through a research study ten years ago. In 2007, Renu wrote a paper, based on case studies of college students in Delhi, focussing on how young people with disabilities conceptualise the body, sex and marriage.<sup>68</sup> It highlights the difficulties of a person with disabilities in finding a partner. It 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.

68 ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity.

Even organisations working with people with disabilities often did not pay attention to issues of sexuality. Women's Health Training Research and Advocacy Cell (WOHTRAC), based in Vadodara, Gujarat has been working since 1992 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 that was moderated by Janet Price. As part of the same meeting, a needs assessment appraisal was conducted among organisations that 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 were 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>69</sup>

69 KHANNA, R., et al. 2004. Consultative Meet on Gender and Disability.

However, the reality is that sexuality concerns are very real for people with disabilities. In an undated yet current and relevant interview Renu Addlakha states the case with clarity:

At core sexuality is essentially about acceptance of self and acceptance by others. It is an integral part of human life and not a matter of shame and guilt. Given the oppression suffered by persons with disabilities, there is every reason to believe it is a matter of utmost importance in the movement for total inclusion of persons with disabilities in the social mainstream. Sexuality education is not just about body parts and reproductive education. It is equally about self-awareness, self-esteem, self-protection and relationships.<sup>70</sup>

70 BHAMBHANI, Dr.M. and SINGH, P. Adolescents, youth with disabilities unable to access programmes targeting sexuality: Renu Addlakha. *Disability News and Information Service (DNIS)*. Retrieved from [http://www.dnis.org/print\\_interview.php?interview\\_id=70](http://www.dnis.org/print_interview.php?interview_id=70)

Reflecting on her own experience as a woman with a disability, Anita Ghai said, "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 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 said 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....” asserted Dr. Balaiah Donta from the National Institute for Research in Reproductive Health (NIRRH).

Geeta Chaturvedi from Khushboo Welfare Society pointed out, “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. In a 2014 article in an online paper, she says, “One needs to understand that persons with disabilities are mostly denied their sexual rights. But their biological needs are same as others. Sometimes, they do not know where and how to behave. For example, one can see adolescents with mental disabilities trying to masturbate in public – we need to teach them when and where this is acceptable.”<sup>71</sup>

According to Shalini Khanna, Director of the Centre for Blind Women, National Association for the Blind, “Adult blind women

71 MASOODI, A. (2014. December 3). Sexual rights of disabled women. *Live Mint*. Retrieved from <http://www.livemint.com/Politics/FDPpol4lJopXo37spUU1kL/Sexual-rights-of-disabled-women.html>

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.

Jhilmil Breckenridge, poet, writer, artist and mental health and domestic violence activist, says in a 2017 online article:

The sexual and reproductive rights of the disabled, especially the mentally ill, are not considered important. Policy makers, activists and the carers of the disabled do not press enough for these, and the mentally ill do not have a loud enough voice. Further, the sexual rights of men and women with mental illnesses who are incarcerated are not discussed to any adequate degree.<sup>72</sup>

72 BRECKENRIDGE, J. 2017. People with mental illnesses who are incarcerated face a near-total denial of their sexual rights. Retrieved from <http://blog.sexualityanddisability.org/2017/03/people-mental-illnesses-incarcerated-face-near-total-denial-sexual-rights/>

This connection between human rights and sexual rights of women with (psychosocial) disabilities is well articulated in a 2017 publication by the Asian-Pacific Resource & Research Centre for Women (ARROW), *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*:

Some of the critical issues around the rights of women with psychosocial disability are intimately connected with their ability to exercise their sexual rights, for instance, the right to privacy, bodily integrity, competence and capacity for sexual (and other kinds of) decision making, consent, autonomy, nondiscrimination and so on. Advocating for these human rights for women with psychosocial disability would in fact form the enabling conditions for meaningful fulfilment of sexual rights.<sup>73</sup>

73 RANADE, Ketki, and Anjali—Mental Health Rights Organisation. *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*. Kuala Lumpur: Asian-Pacific Resource & Research Centre for Women (ARROW), 2017. Retrieved from <http://arrow.org.my/publication/sexual-rights-women-psychosocial-disabilities-india/>

And it is not only people with disabilities or those working with them who feel the acute absence of information on sexuality and services on sexual and reproductive health, but also parents and other caregivers of people with disabilities. 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.

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. Drawing from her experiences working with parents of persons with intellectual disabilities, Sameera Shamim says, "I found some mothers who used to masturbate their sons and help them experience it. This helped them also create a bond with the child, provide the child with the pleasure and experience, teach the child how to do it and also appropriateness. Though it was very difficult for the mother to go through this journey". This is a controversial area of debate within the disability and sexual rights fields. Some advocates believe this approach is acceptable while others believe it borders on abuse. Many people argue that such situations may not be perceived within a simple frame of right and wrong, black or white.

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.

To address sexuality concerns with accurate, accessible and age appropriate information requires sustained investment of time, material, educational and trained human resources. This remains a challenging area. Attitudes to sexuality education in schools as reflected in the comments made by influential stakeholders are disheartening and must continue to be debated.<sup>74</sup> In the draft National Education Policy 2016, the original text is reported, in the news, as having used the word ‘sexual’ in the context of providing information and education on reproductive and sexual health needs. This word was removed altogether as a result of inputs from the Human Resource Development Ministry.<sup>75</sup> Perhaps it is also significant that it is difficult to find online sources of information on the debates or discussions that have gone into the drafting of the NEP, particularly with reference to sexuality education. The current draft as accessed in January 2017 from the website of the Ministry says of adolescent education, ‘The Adolescent Education Programme and National Population Education Programme will be integrated into the curriculum of schools in a phased manner.’<sup>76</sup>

Given these factors, it is challenging to speak of sexuality in the context of children with disabilities. However, it is still a subject that requires to be reflected upon and discussed with respect and empathy for families and carers as well as for children themselves, since the majority of this population is in a state of unaddressed anxiety due to ignorance around these subjects.

In 2016, along with partner organisations, CREA undertook a needs assessment survey and study using the lens of sexuality, to understand the situation of field organisations in West Bengal, Tamil Nadu, Maharashtra and Delhi, working on issues of disability (hereafter referred to as the CREA report).<sup>77</sup> Most of the participating organisations worked with people with multiple disabilities and intellectual and Psychosocial disabilities. Hearing

74 JHA, D. (2014. June 27). Sex education in schools should be banned, Union health minister Harsh Vardhan says. *Times of India*. Retrieved from <http://timesofindia.indiatimes.com/india/Sex-education-in-schools-should-be-banned-Union-health-minister-Harsh-Vardhan-says/articleshow/37274947.cms>

75 MOHANTY, B. (2016. October 24). ‘Sex’ out of sex education. *The Telegraph*. Retrieved from [https://www.telegraphindia.com/1161024/jsp/frontpage/story\\_115250.jsp#.WGzGRdL3TTI](https://www.telegraphindia.com/1161024/jsp/frontpage/story_115250.jsp#.WGzGRdL3TTI)

76 GOVERNMENT OF INDIA. MINISTRY OF HUMAN RESOURCE DEVELOPMENT. Some Inputs for Draft National Education Policy 2016. Retrieved from [http://mhrd.gov.in/sites/upload\\_files/mhrd/files/nep/Inputs\\_Draft\\_NEP\\_2016.pdf](http://mhrd.gov.in/sites/upload_files/mhrd/files/nep/Inputs_Draft_NEP_2016.pdf)

77 CREA, ANJALI MENTAL HEALTH RIGHTS ORGANISATION, POINT OF VIEW, EQUALS CENTRE FOR PROMOTION OF SOCIAL JUSTICE and SRUTI DISABILITY RIGHTS CENTRE *Needs Assessment Report- Addressing Disability and Sexuality Rights, Closing the Gap – Building Institutional Capacity to Address Sexuality and Disability*. (2016) (Unpublished Draft)

and speech impairment, visual impairment, multiple sclerosis, developmental disabilities (cerebral palsy, autism) and physical and locomotor disabilities were amongst the other areas of focus of the organisations. The survey intended to find out how equipped these organisations are to deal with issues of sexuality amongst the constituencies that they work with. Some of the responses from participants are significant, as they reflect a reality where myths and ignorance about sexuality and disability persist, contributing to rights violations and abuse. Some respondents are reported as having said:

“For pwd male or female problems are the same. Girls with disabilities of course we need to keep more restrictions on time and all.”

“And when boys are sexually abused, they become homosexuals. However the parents do not want that boys will be taught about sexual abuse.”

“Human beings have not degraded so much that they will harass or abuse the blind woman. In thirteen years we haven’t heard a single case.”

These misplaced ideas clearly stem from lack of information. However, research conducted with young persons with disabilities themselves finds that they are quite articulate in voicing their desires and needs.

In a 2012 research paper based on a case study in Akshay Pratishtan, a Delhi based NGO that works with young people and children with disabilities, the author Pham Do Nam notes:

Firstly, young people with disabilities consciously perceived themselves as sexual beings. Nevertheless, sexual conduct and experiences differ between males and females. While men actively express their sexual desire in actual solo or partnered sexual acts, the women find themselves sexually aroused in a psychological and sensual way. Being sexual for men is linked to actual sexual activities while for female is linked to marriage

78 PHAM, D.N. 2012. *The voices unheard – Exploring how young people with disabilities view and experience their growing up as sexual beings: A case study in AkshayPrathisthan, New Delhi, India*. Children and Youth Studies (CYS), International Institute of Social Studies. Retrieved from: <http://hdl.handle.net/2105/13286>

and children. This is caused by gender differences, which determine specific gender roles that shape the social constructed notion and expectation of being a boy and being a girl.<sup>78</sup>

The research study based in Akshay Prathisthan involved individual conversations and group discussions (among other methods) with young people between the ages of 18 and 26 years who have mild and moderate, mental and physical disabilities. It is therefore based on the voices and perceptions of those who experience the issues related to disability and sexuality first hand, and on their understanding of their own selves as sexual beings. Below are some of the responses they made in interviews with the researcher. The parts within brackets are the interviewer prompts.

**(Female voices)**

*“I don’t feel comfortable being touched by male friends but I like to attract their attention”*

[how?...]

*“by taking care of my appearance. The feeling of being appreciated is so good*

[Do you have any idea if comments given to you are good or bad ones? ...]

*“I don’t know but I can tell from their facial expression that they talk about me and I feel proud of myself”*

*“Boys think that I am a normal girl so I become more confident. Some even come and ask for my phone number when I am at a supermarket”*

*“I like dressing up and I like nice clothes. I don’t want to have a boyfriend because my mother says it is not good for me but I like having boys look at me. I feel happy.”*

*“I like to be pretty. I put Kajal on every day [Kajal is a black solid*

made from charcoal used by Indian women to emphasize their eyes, commonly known as eye liner].

*“Every women want to be beautiful so do I but simply my disability restricts my mobility so I don’t have many chances to meet up with male friends”*

*“When I was so sick, I could not sit or walk, I just lied down on bed. My neighbors told my mother not to take me to the hospital for treatment because they say that I am useless, I am just a burden. No one will marry me and if there is someone marrying me. My parents have to pay a big amount of dowry since I am not normal”.*

*“Sometimes, I feel so lonely, particularly when my friends go out with their boyfriends. I also want to have someone nearby to share everything with.*

[So do you also want to have a boyfriend?]

*“My disability does not allow me to have a boyfriend”*

[but your feeling is there, isn’t? that you feel lonely and you want to be loved?]

*“Yes, I have those feelings but I don’t think this will happen to me, you can see, no one will love and want to be with a person in a wheelchair like me “ (pointing at her wheelchair)”*

### **(Male voices)**

*“I feel sad when people do not accept us for who we are, also as human beings like anyone. They judge us by our disabilities and ignore our feelings and desire”*

*“At first, I did not want to be in relationship with anyone. I am scared of how people look at my disability and me.”*

*“Girls don’t love me, they are scared of my disability”*

*“When I am in a relationship, I feel happy and more confident. I feel love and to be loved”*

*“I like talking about girls with my friends; we talk about their bodies, boobs, shapes of their bottoms” (laugh)*

*“I masturbate when I am at home alone; sometimes I visit [pause] porn websites to get aroused and then take care the rest by myself” (grin)*

[Don't you have sex with your girlfriend?]

*“We only meet each other once a week, sometimes twice; I just masturbate when I feel like having sex”.*

*“Of course, I am sexual being, no matter what people say. I have a girlfriend now, even though we have not thought of getting married yet but I am happy with my life now, just as any normal people.”*

*“I am sexual being, I know how to love a girlfriend and I know how to make children” (laugh)*

The young people quoted in the box above seized the opportunity when it presented itself to speak about themselves. Voices such as these are important. The platforms are still few, but there is an increasing consciousness of the need to speak of disability and sexuality and to listen to expressions of the thoughts, observations and desires of those for whom disability is a personal experience, a lived reality.

In 2016, the Foundation for Social Transformation (FST) sought to understand the sexual and reproductive health needs of young people with disability in Assam, India through exploring the experiences of youth with disabilities (YwD), specifically focusing on sexual violence, sexual health, and sexuality (hereafter referred to as the FST study or FST report). The age range of participants was 15-25 years. It was not easy for them to find field investigators to conduct the study because of the inhibitions and social stigma associated with sexuality and sexual health, apart from constraints of time and availability. FST found that, “63 YwDs (77%) felt that it is

important to discuss issues around growing up, menstruation, sex, love, relationship, attractions, safe touch, unsafe touch, marriage and violence with them. Only four respondents felt that it was not important.”<sup>79</sup>

The FST report includes quantitative findings as well as anecdotes documented during the course of the study. One such anecdote tells of a young girl with intellectual disability:

Joymoti (name changed), was a very lovable young girl. She was under care at the Sanjivani Hostel. She was intellectually challenged. Joymoti loved to talk and when talking to boys, she would often propose them for marriage. As Joymoti kept pestering her guardians for a mobile phone, they gave her one on pretext, though it was not in working order. Most of the time, she was observed talking on that phone by herself where she would be proposing to the (imagined) person on the other side. Even while travelling, she would carry her mobile and was observed extending marriage proposals throughout the phone conversations. Sometimes, Joymoti would hug and kiss the person sitting next to her, out of the blue. These were all observations made by her caregivers but they were never considered a matter of concern.<sup>80</sup>

This example of the lack of concern and understanding of issues related to disability, sexuality and relationships may well be representative of the experiences of many people.

As has amply been demonstrated, the rights of the people with disabilities, their desires for expression and pleasure are neglected. Myths that people with disabilities are non-sexual 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. 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

79 FOUNDATION FOR SOCIAL TRANSFORMATION. 2016. *Understanding Sexual Health & Rights of Youth with Disabilities in Assam - A Study.*

80 Ibid.

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 Sameera Shamim points out, while the discourse on rights, choice and pleasure is gaining some ground, though still very limited, in mainstream debates, however the mention or inclusion of persons with disabilities is almost completely missing. The gaps are due to the lack of confidence or prioritisation of this right by persons with disabilities themselves, as they are overwhelmed by other struggles and thus sexuality and rights takes a back seat. At the same time, mainstream discussions also often leave them out.

## 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 depends on where a person is placed on the intersection of these variables. However, except in the case of people with severe multiple disabilities and/or intellectual disabilities, people with disabilities face many similar issues and concerns as their non-disabled counterparts. For example, regardless of the disability, in most cases, as Janet Price points out, disabled teenagers will go through puberty which brings challenges of new sexual awareness and changing bodies. They need support to develop self-confidence and respect, exposure to build understanding of their own sexuality, and education about how to manage bodily changes both physical as in menstruation/emissions and social/emotional e.g. self-presentation and relationships. Again regardless of disability, all people need information on how to keep themselves clean, 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.

A 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>81</sup>

In 2010, WHO published a guidance document focusing on a programming framework for sexual health.<sup>82</sup> In a section on the impact of physical disabilities and chronic illnesses, the document states:

The sexual needs and expressions of people with these disorders are often ignored, because there is a perception that they are not – or should not be – sexually active. Some chronic illnesses also have a negative impact on sexual health. Certain cancers, particularly those associated with the reproductive system, combined with the effects of the often radical treatment involved, can profoundly affect a person’s sense of their sexuality and sexual functioning.

The document also says, “A sexual health framework might include the creation of policies to increase the social acceptability of sexual expression by people with a disability or chronic illness.”

This leads us to further explore the sexuality issues of people with disabilities in comparison to those who are not disabled. While some issues are the same for everyone, people with different disabilities do face different issues.

81 WORLD HEALTH ORGANISATION and UNFPA. 2009. Promoting Sexual and Reproductive Health for People with Disabilities. Retrieved from [https://www.unfpa.org/sites/default/files/pub-pdf/srh\\_for\\_disabilities.pdf](https://www.unfpa.org/sites/default/files/pub-pdf/srh_for_disabilities.pdf)

82 WORLD HEALTH ORGANISATION. 2010. Developing sexual health programmes.



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.”

TARSHI’s own experience of working with girls with visual impairment also reflects how the lack of opportunities and source of information often leads girls to share the limited information they may have amongst themselves. This information may not always be true or correct and is often based on the limited exposure or experience of girls within the group. This is often found to be dangerous as misinformation or incorrect information gets shared and believed.

A critical issue is that, 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.

As C. Mahesh, with Community Based Rehabilitation Forum (CBR Forum), Bangalore, said, “There is a tendency for field staff to work on issues of sexual and reproductive health and rights (SRHR) 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, reflected 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 ‘not-very-severe’ physical disabilities what have been termed ‘the able disabled’ people. 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”.

Some sexuality issues are the same for all, while some others are different. As Merry Baruah from Action for Autism illustrated, “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 counselling, training and research organisation working to promote positive change in individuals, said 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 (at the time of writing the 2010 Working Paper) in Delhi, spoke 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.” These experiences corroborate TARSHI's experiences of working with educators and care providers of children and young people with disabilities since the late 1990s.

The experience of disability is mediated by variables of social power or vulnerability, including sexuality, sexual orientation, 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.

That people with disabilities are not a homogenous group is obvious. It must be noted that the experience of disability is unique to every individual and varies across gender, caste, class, age and the presence of more than one disability. As Janet Price points out, “It is also important to consider other intersectional aspects such as caste and the position of tribal and indigenous disabled people”, and draws attention to the Disability Justice approach mentioned earlier in the discussion of models of disability. It is important to return to this approach and understand another aspect of it that focuses on the challenges faced by people with disabilities who are in contact with the justice system, as a witness, a victim or a perpetrator of crime.<sup>83</sup>

83 ASSOCIATION OF CHILDREN’S WELFARE AGENCIES, INTELLECTUAL DISABILITY RIGHTS SERVICE and LIFE WITHOUT BARRIERS. Disability Justice Project. Retrieved from <http://www.disabilityjustice.edu.au/background-to-the-project>

The Critical Social Justice blog of the University of Maryland, Baltimore County (UMBC) Women’s Center presents the concept thus:

Disability justice is the continuation and expansion of disability rights, a movement that sought equal rights and access for disabled people, but was often constrained by its focus on mostly white and male individuals. Disability justice uses an intersectional lens to bring a more nuanced and active approach to the movement. By challenging assumptions about ability and embracing all kinds of bodies, the disability justice framework looks beyond the commonality of disability to incorporate other identities.<sup>84</sup>

84 UMBC WOMEN’S CENTER. 2016. What You Need To Know About Disability Justice. Retrieved from <https://critsocjustice.wordpress.com/2016/10/17/what-you-need-to-know-about-disability-justice/>

These ‘other identities’ that the Disability Justice approach talks about depend on where one is placed on multiple axes of power and affects what one is able to access in terms of information, opportunities and services. Kiran, a female to male transgender

person and wheelchair user, shares how multiple intersections played out in his own life. Kiran was born in Warangal, in South India and is a member of an *adivasi* community, the Lambani tribe. Childhood polio caused lower limb paralysis as a result of which he spent many years as a child not going to school or the playground and isolated from the company of other children. His situation was made more complex by the fact that he belongs to a tribal community. Kiran said, “The traditional bias against ‘girls’ was very strong, especially in this Lambani tribe. Besides, I was paralysed and was confined to the house. Not going out, lack of socialising, no schooling – and also the innate fear around security of a girl. My parents even brought me up as a ‘boy’; short hair, short pants instead of a skirt!”<sup>85</sup> He went to school for nine years, after the intervention of a teacher who spoke to his parents convincing them to send him to school.

Speaking of his experiences when grappling with sexual and gender identity issues, Kiran remembers that in school he “had problems, no friendship (with anyone), no independence, no interest (in anything)”. Dressing was a problem – he wore shorts and they said a girl ‘should dress like a girl’. He completed Class 10 at the age of 18 and then went for further studies to a hostel 40 kilometres away, again due to the encouragement and support of the same teacher. As he says, “I did not like it there – it was an all girls hostel, but I felt like a boy, and could not make friends.” This is when he met another young person with a disability. She and Kiran became friends and together they began to work for the rights of other students and persons with disability. Around this time, he met a woman who fell in love with him. Kiran and she had a runaway temple marriage, against enormous opposition. This opposition was strong and a traumatic sequence of events unfolded in his life. The timely intervention of a crisis team run by an NGO working in the sexuality and rights sector helped them. This proved to be another turning point in his life and it was at this stage, when there were support persons to speak to about sexuality and identity, that Kiran began to identify and understand his own gender and sexuality. He says, “Until then, I did not understand anything about sexuality; I

85 ALEYA, S. 2017. An interview with disability and sexuality rights activist Kiran. In *Plainspeak*, TARSHI. Retrieved from <http://www.tarshi.net/inplainspeak/interview-disability-and-sexuality-rights-kiran/>

only understood love, not sexuality, gender, body, or any of these things”.

In Kiran’s story we see how disability, sexuality, gender expression and identity, caste status, and rural location, among other factors, come together to create multiple and intersecting levels of discrimination. Here’s how he sums it up: “In this society, people with disabilities face discrimination, especially those who are from a marginalised community, and then, as a sexual minority there is double discrimination. So as a female-born sexual minority with a disability, my experience is that acceptance is low.”

This, even after the ground-breaking recognition by the Supreme Court of the transgender community. In 2014, the Supreme Court in response to a Public Interest Litigation (PIL) filed by National Legal Services Authority (NALSA) gave a ruling that granted legal recognition to the transgender community in India.<sup>86</sup> In this ruling, the bench clarified their understanding of the transgender community as comprising of “Hijras, eunuchs, Kothis, Aravanis, Jogappas, Shiv-Shakthis etc.” The ruling also clarifies that, “The grammatical meaning of ‘transgender’, therefore, is across or beyond gender. This has come to be known as an umbrella term which includes gay men, lesbians, bisexuals and cross dressers in its scope. However, while dealing with the present issue, we are not concerned with this aforesaid wider meaning of the expression transgender.” The judgment affirmed the human rights of transgender people and their rights to education, social assimilation, and employment among other human rights.

A 2016 report based on a survey of attitudes towards transgender people conducted across 23 countries including India by BuzzFeed News, polling firm Ipsos and The William’s Institute: UCLA School of Law found that 82% of Indians supported the 2014 Supreme Court order protecting transgender rights, and that 64% believed that transgender people should be allowed to conceive or give birth to children while 73% believed they should be allowed to adopt children.<sup>87</sup> The report also found that Indians “were less familiar

86 NALSA vs Union of India and others, 2014. Retrieved from [http://orinam.net/377/wp-content/uploads/2014/04/Judgement\\_Nalsa\\_Transgenderrights.pdf](http://orinam.net/377/wp-content/uploads/2014/04/Judgement_Nalsa_Transgenderrights.pdf)

87 FEDER, J. SINGER-VINE, J. & KING, B. (2016. December 29). This Is How 23 Countries Feel About Transgender Rights. *BuzzFeed*. Retrieved from [https://www.buzzfeed.com/lesterfeder/this-is-how-23-countries-feel-about-transgender-rights?utm\\_term=.qyV69oEV1#.xkdNEqoda](https://www.buzzfeed.com/lesterfeder/this-is-how-23-countries-feel-about-transgender-rights?utm_term=.qyV69oEV1#.xkdNEqoda) and

THOMAS, S. (2017. January 10). Here’s What India Thinks Of The Transgender Community. *BuzzFeed*. Retrieved from [https://www.buzzfeed.com/soniathomas/indians-overwhelmingly-support-protections-for-transgender-p?utm\\_term=.qp9rZ3Y46#.owKovdVqY](https://www.buzzfeed.com/soniathomas/indians-overwhelmingly-support-protections-for-transgender-p?utm_term=.qp9rZ3Y46#.owKovdVqY)

with transgender people than people in many other countries in the survey” with only 20% saying they know a transgender person. Indians also expressed less comfort with transgender people than with people who identify as gay or lesbian. Significantly, 69% of Indians said that they believed transgender persons have a form of physical disability, while 57% felt that they have a form of mental illness. This response seems to place a double burden of stigma, combining disability and sexuality in the way persons who are transgender are perceived. This is an interesting point to note because while the respondents seemed to be in favour of protecting the rights of transgender people, they also believed that transgender people have a form of physical disability and mental illness. The response also reflects a typical approach that sees disability as located in an individual rather than disability as being the interaction between a person living with impairment and the attitudinal and environmental barriers around them. In this case, being transgender is seen framed purely as a disability, not as an issue of selfhood or sexual and reproductive health and rights.

Experiences from the field that reflect community norms and socio-cultural barriers reveal other aspects of the links between poverty, psychosocial and emotional vulnerability and disability, and sexuality and sexual health. Sex and sexuality are most often terribly stigmatised and therefore difficult subjects to raise or discuss. The impact of dealing with issues so stigmatised may lead to experiencing emotional isolation, stress and depression.

The Bapu Trust works extensively with local communities in the *bastis* (low income urban settlements) of Pune on issues of community support and inclusion of persons with Psychosocial and intellectual disabilities. According to Bhargavi Davar, founder of The Bapu Trust, “In the low income community they don’t talk a lot about sexuality or sexuality education. Sexuality is around them all the time but do they actually talk about these things?” In one case, a young adult man who was suicidal would keep calling Bhargavi for phone counselling. This young person had questions about himself and sexuality. Along with the counselling, she gave him a referral to

a sexologist and this was very useful, reducing his levels of anxiety and depression. “There are issues about privacy. For example, there was another case of a man in his mid forties with sexual needs not expected at his age perhaps, by his adult children and family. Living in a small space, his expression of sexual need led to abuse of him by his grown up children who were unable to accept this. There is a great need to talk about this in the *basti*.” Social stigma and self-stigma impact both mental health and help seeking behaviour in multiple ways. Challenging the stigma surrounding sexuality is crucial as this stigma contributes to abuse and rights violations in different ways.

Bhargavi points out, “Educating families becomes the big challenge as there is so much stigma attached to a woman’s sexuality. The problem becomes extremely complex when there is an individual woman who may express high sexual need. Also, single women in the community are a demographically significant population. There are 8 to 10% of women in a *basti* who are widows, many with young children. So these are single women headed households. Generally they turn to a life of austerity. The widowed women who tend to maintain the garb of the married woman, with the jewellery etc, tend to be stigmatised.” In another case, a young boy spoke of having been sexually abused by men in the *basti* due to gang wars. During his counselling sessions with Bhargavi, he showed extreme discomfort with finding the words around communicating his experiences of sex and sexual abuse. According to Bhargavi, “Awareness about sexuality and sexual issues is low and there is direct impact on mental and emotional health. Suicidal ideation is often seen.”<sup>88</sup>

88 Bhargavi Davar. 2017.  
Personal communication

Another organisation, The Banyan, has been working for 24 years with the very marginalised homeless women (and now men as well) with mental illnesses and avails of open platforms for discussions for them to share perceptions, experiences, and sexual needs as they emerge, and sees these as part of their essential well-being. Dr. Lakshmi Ravikanth of The Banyan points out, “Voices of persons with mental health issues, languishing in institutional care,

especially the homeless and marginalized, are muted. Sexuality concerns, preferences, alternate, compromised choices, sexual health, hygiene etc. of persons with disability need expressions, in open discourses, small group conversation and individual specific contexts. Mere information and directions do not suffice; risks need to be taken with caution so as to protect the rights of persons living with mental illness, and of the organisation, and learn from each incident as to how to enable desire with protection.”<sup>89</sup>

89 Lakshmi Ravikanth. 2017.  
Personal communication

As we see in this section, the experience of disability is influenced by many different factors and this leads to people having different needs and concerns. Similarly, no two people experience or express their sexuality in exactly the same way, despite 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 in different parts of their body and yet another may need to be taught how to pleasure themselves.



# THE POLICY CONTEXT

Moving on from lived experience and ground realities let's look at the policy context to see how and how far people with disabilities are included because 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 cannot 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>90</sup>

<sup>90</sup> BHANUSHALI, K. 2007. Changing Face of Disability Movement.

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.

Now disability and rights have become an increasingly familiar part of public discourse through the efforts of many activists and self-advocates in many different parts of the world. Familiar elements of an evolving 21<sup>st</sup> century framework include:

Campaigns at the local, national and international level;

Interpreting and implementing strategies of support and inclusion;

Opening up and increasing accessibility across spaces using a rights based approach;

Raising awareness;

Changing the way in which society views issues of disability.

The framework is taking shape at different paces, in different ways, citizen led, driven by persons with disabilities, identifying and challenging rights violations, taking a cross-sectoral approach and advocating for change in law, policy and administration. Importantly, media and public information and opinion are playing a bigger role in connecting people and ideas on the ground. In various online articles<sup>91</sup> and blogs, disability activism, advocacy and issues of policy are making inroads into a space of public discourse. Social media now plays a large role in engaging people, involving them in the conversation, fostering an environment where the voices and experiences of self-advocates are shared in the wider public space.

As Sameera Shamim observes, “There has also been an increase in knowledge and information with respect to rights, entitlements, and various social schemes available for people with disabilities in the Indian context. There are many organisations working at the grassroots which may not be working for disability rights in a focused manner but are actively including people with disabilities in access to entitlements at the level of urban and rural governance. The Internet has led to an increase in information, portals are run especially for disability and services related to disability needs which helps care providers and persons with disabilities to be better informed and aware of their rights. Though numerically this is still a minority.”

91 THE GUARDIAN. (2016. June 29). 10 activists changing lives for disabled people around the world. Retrieved from <https://www.theguardian.com/global-development-professionals-network/2016/jun/22/10-activists-changing-lives-disabled-people-around-world>

## International Documents and Developments on Disability and Rights

92 UNITED NATIONS. 1993. The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. Retrieved from <http://www.un.org/esa/socdev/enable/dissreoo.htm>

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>92</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 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 SRHR are highlighted 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 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 for a person with disabilities from the perspective of forming a family, getting married or becoming a parent. 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.

Janet Price argues: “As disabled people, it is important that we see and hear ourselves represented in film and on TV and radio, as everyday yet varied examples of people living our lives, dressing up for parties, doing our jobs, falling in and out of love, negotiating marriage. We are tired of being shown only as tragic or exceptional cases.” The film *AccSex* by Shweta Ghosh is an in-depth look at the relationships of four people with disabilities and their experiences of dating, love, marriage, work and life in an Indian city. It is also important that disabled people are involved in the creation of culture, the production of film, plays, dance, TV. Nidhi Goyal is a comedy performer, addressing sexuality and disability from the perspective of a single woman in India, facing down the marriage market and the mis-perceptions about blindness. In 2017, she appeared on a TV

comedy talent show *The Rising Stars of Comedy*<sup>93</sup>, speaking of the rights of disabled people to representation, to sexuality – and to humour.

There are many different organisations working on disability issues in different countries. In 2008, United Nations High Commissioner for Refugees (UNHCR) developed a non-exhaustive list of NGOs and UN agencies that are internationally recognised and have a strong presence in their region<sup>94</sup>. This listing includes organisations such as the International Disability Alliance (IDA), Inclusion International, CBM (an international organisation working on issues of disability and inclusion) and Workability International. Some of these organisations clearly articulate their focus as rights based, in alignment with the UNCRPD.

IDA for example, was established in 1999, and is now a global and regional network with over 1100 organisations of persons with disabilities and of their families.<sup>95</sup> IDA promotes implementation of the UNCRPD and focuses on issues of compliance by governments to the provisions of the UNCRPD. Workability International, with 130 member organisations across 40 countries, states on their website, “People with disabilities should have legal rights to equal opportunities and non-discrimination in all aspects of their lives. Only by providing practical opportunities for employment can we add weight and meaning to such rights.”<sup>96</sup> Inclusion International, with 200 member federations across 115 countries, is a global federation of family-based organisations advocating for the human rights of people with intellectual disabilities worldwide.<sup>97</sup> CBM International advocates for inclusion following UN guidelines in powerful, international policy-making bodies, and campaigns and raises funds through its Member Associations.<sup>98</sup>

Ten years after the UNCRPD was adopted, Vladimir Cuk, (Executive Director, IDA), and Dominic Haslam, (Board Member, International Disability and Development Consortium), wrote in an article:

Since its adoption, the CRPD has raised awareness about disability as both a matter of human rights and of development.

93 NDTV PRIME. (2017. June 9). *This Stand-Up Comedian With Disability Is An Inspiration For All*. [Video file]. Retrieved from <https://www.youtube.com/watch?v=QC5Hka4Mq6I>

94 UNHCR. 2008. NGOs & UN Agencies Assisting Persons with Disabilities. Retrieved from <http://www.unhcr.org/4ec3c78c6.pdf>

95 INTERNATIONAL DISABILITY ALLIANCE. Available at <http://www.internationaldisabilityalliance.org/>

96 WORKABILITY INTERNATIONAL. Available at <http://www.workability-international.org/about-workability>

97 INCLUSION INTERNATIONAL. Available at <http://inclusion-international.org/who-we-are/>

98 <http://www.cbm.org/In-Action-250903.php>

It also marks a paradigm shift, where persons with disabilities were no longer viewed as objects of charity but as active members of societies, in charge of their own lives, with free and informed consent and with the same rights to participation, engagement and inclusion, as everyone.

This is why, as negotiations began around the new global Sustainable Development framework to follow the Millennium Development Goals (MDGs), the CRPD was used as a foundation by many disability organisations, including the International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC), to lobby for the inclusion of persons with disabilities in international development policy. The movement came together to ensure that when “leave no one behind” was adopted by the UN as an overall mantra for the new Sustainable Development Goals (SDGs) – that this included persons with disabilities in a meaningful and measurable way. It marked a huge step forwards from the MDGs, where the evidence shows that people with disabilities were systematically excluded.<sup>99</sup>

99 CUK, V. and HASLAM, D. (2016. June 12). How 10 Years Of The CRPD Have Been A Victory For Disability Rights. *The Huffington Post*. Retrieved from <http://www.huffingtonpost.com/entry/58473671e4b0cc9e7cf5dbdd?timestamp=1481064573703>

Organisations such as IDA have brought focus on the sexual and reproductive health rights of persons with disabilities at international fora. In 2010 for example, the Committee on Economic, Social and Cultural Rights (CESCR) held a Day of General Discussion on Sexual and Reproductive Health Rights, to which IDA made a submission that states:

Women and girls with disabilities experience double discrimination which places them at a higher risk of gender based violence, sexual abuse, neglect, maltreatment, harassment and exploitation. They suffer violence both within and outside the home including rape (also marital rape), forced marriages, female genital mutilation (FGM) and other harmful practices, and most often health and community professionals are not trained to treat the negative reproductive health consequences of FGM such as infections, obstructed

labour, perineal tears, fistula and infertility bearing upon them. Women and girls with disabilities are also subjected to forced abortion, forced contraception (including pills, injections and intrauterine devices – IUDs), and forced sterilisation (hysterectomy, tubal ligation, Essure). Boys and men with disabilities have also been subjected to forced sterilisation (vasectomy) or chemical castration. They have been equally neglected in being informed about their rights and as a consequence are often ill-equipped to take on the responsibility of their own reproductive and sexual behaviour and health.<sup>100</sup>

Among the recommendations IDA made to the Committee on Economic, Social and Cultural Rights (CESCR) in this document is:

To elaborate and adopt a General Comment on the right to sexual and reproductive health which comprehensively addresses the situation and concerns of children and adults with disabilities by upholding the rights inscribed in the CRPD, including to consult closely with DPOs (organisations run by persons with disabilities, especially membership-based organisations of persons with disabilities) in the drafting process of the General Comment (Article 4(3), CRPD: “In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations”).<sup>101</sup>

100 INTERNATIONAL DISABILITY ALLIANCE. 2010. IDA submission to the Committee on Economic, Social and Cultural Rights Day of General Discussion on Sexual and Reproductive Health Rights. 15 November 2010. Retrieved from <http://www.internationaldisabilityalliance.org/resources/submission-right-sexual-and-reproductive-health>

101 Ibid.

IDA in collaboration with the United Nations Population Fund (UNFPA) currently runs the Youth with Disabilities Programme. The first of the stated main goals of this programme is: “Issues relating to the rights of youth with disabilities – in particular sexual and reproductive health and prevention of sexual and gender-based violence – receive exposure within relevant international human rights and development normative frameworks as well as within



102 INTERNATIONAL DISABILITY ALLIANCE . 2017. Youth with Disabilities Program. Retrieved from <http://www.internationaldisabilityalliance.org/youth>

wider youth movements”.<sup>102</sup>

The UNCRPD Committee on the Rights of Persons with Disabilities, in General Comment No. 3 (GC3), 2016, on women and girls with disabilities, focuses on barriers that “create situations of multiple and intersecting forms of discrimination against women and girls with disabilities” and “neglected aspects” related to women and girls with disabilities. In the Introduction segment, Para 5 of GC3 reads:

Women with disabilities are not a homogenous group. They include indigenous women; refugee, migrant, asylum-seeking and internally displaced women; women in detention (hospitals, residential institutions, juvenile or correctional facilities and prisons); women living in poverty; women from different ethnic, religious and racial backgrounds; women with multiple disabilities and high levels of support; women with albinism; and lesbian, bisexual and transgender women, as well as intersex persons. The diversity of women with disabilities also includes all types of impairments, in other words physical, psychosocial, intellectual or sensory conditions that may or may not come with functional limitations. Disability is understood as the social effect of the interaction between individual impairment and the social and material environment, as described in Article 1 of the Convention on the Rights of Persons with Disabilities.<sup>103</sup>

103 UNITED NATIONS. Committee on the Rights of Persons with Disabilities. 2016. General Comment No 3. Article 6: Women and girls with disabilities (Adopted 26 August 2016). Retrieved from <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

Having established this multi-layered context, GC3 articulates recommendations for national implementation in part V. These include:

Para 63 - (States parties should combat multiple discrimination by, inter alia: ) (a) Repealing discriminatory laws, policies and practices that prevent women with disabilities from enjoying all the rights enshrined in the Convention, outlawing gender- and disability-based discrimination and its intersectional forms, criminalizing sexual violence against girls and women with disabilities, prohibiting all forms of forced sterilization,

forced abortion and non-consensual birth control, prohibiting all forms of forced gender- and/or disability-related medical treatment and taking all appropriate legislative steps to protect women with disabilities against discrimination;

and

Para 64 – (States parties should take all appropriate measures to ensure the development, advancement and empowerment of women with disabilities by, inter alia:) (b) Adopting affirmative action measures for the development, advancement and empowerment of women with disabilities, in consultation with organisations of women with disabilities, with the aim of immediately addressing inequalities and ensuring that women with disabilities enjoy equality of opportunity with others. Such measures should be adopted in particular with regard to access to justice, the elimination of violence, respect for home and the family, sexual health and reproductive rights, health, education, employment and social protection. Public and private services and facilities used by women with disabilities should be fully accessible in compliance with article 9 of the Convention and the Committee’s general comment No. 2 (2014) on accessibility, and public and private service providers should be trained and educated on applicable human rights standards and on identifying and combating discriminatory norms and values so that they can provide appropriate attention, support and assistance to women with disabilities;

Documents such as GC3 expand the opportunity for conversation and advocacy, and are open to varied analysis and interpretation by the international community. For example, Women Enabled International (WEI) has presented a guide online covering the major themes and issues in the document for easier understanding and reference.<sup>104</sup>

In a recent article available online, F. J. Ruiz analyses the concluding observations of the CRPD Committee, and finds that the Committee remains narrow in its approach to sexuality, confined by gender

104 WOMEN ENABLED INTERNATIONAL. 2017. Guide to CRPD General Comment No. 3: Women and Girls with Disabilities. Retrieved from <http://www.womenenabled.org/pdfs/WEI%20Guide%20to%20CRPD%20General%20Comment%20No%203%20on%20Women%20UPDATED%20FINAL%20GC%20TEXT%20April%202017.pdf>

105 RUIZ, F. J. 2017. The Committee on the Rights of Persons with Disabilities and its take on sexuality. *Reproductive Health Matters* Vol. 25, 2017 - Issue 50: Disability and sexuality: claiming sexual and reproductive rights. Retrieved from <http://www.tandfonline.com/doi/full/10.1080/09688080.2017.1332449>

and sexuality binaries and continues, in actual practice, to take a medicalised and protective approach to disability.<sup>105</sup> His hypothesis is that:

The Committee has retained a medical model with regard to sexuality by replicating naturalised, biological, and binary conceptions of gender. Following and strengthening the protective trend, it has confined its deliberations on sexuality to safeguarding women from practices of sexual violence, paying scant attention to sexual self-determination, gender identity, and sexual orientation. This narrow approach to sexuality has failed to address the social stigmas and stereotypes that limit the possibilities of persons with disabilities of expressing and acting upon desire consensually.

Amongst other conclusions in his article, he says:

By narrowing sexual and reproductive rights to instances of violence and force, whose solution is restricted to sex education and information within the medical arena, the Committee has replicated prejudices that equate disability with incapacity, incompetence, impotence, and asexuality. It has also failed to acknowledge the experiences of persons with disabilities with different sexual orientations and gender identities.

Globally, we are seeing an increasing momentum of strategic programme activity and advocacy on the links between sexuality and disability. Activists and organisations are investing themselves in building awareness, campaigning for rights and implementing programmes that promote engagement and solutions to issues of sexuality, disability and rights. There are several voices within the disability rights movements, the SRHR movements and the intersections of the two. For example, while some groups advocate for the right to marriage for people with disabilities, Janet Price points out that there are some conservative groups advocating for limits on marriage – to define it as between a man and a woman (biological) and some also want limits on capacity. This would imply that people with severe physical and psychosocial disabilities

would be excluded if these groups get their way.

Closer home, in the South and Southeast Asia region, in 2010, UN Economic and Social Commission for Asia and the Pacific (ESCAP) launched the regional campaign, ‘Make the Right Real’.<sup>106</sup> This was followed by the articulation of the Incheon Strategy in 2012, identifying ten goals for this campaign in the Asian and Pacific region.<sup>107</sup> These goals address issues of poverty and livelihood, participation, access, social protection, intervention and education, gender, disability-inclusive disaster risk reduction, disability data, implementation of the UNCRPD, and regional cooperation. The introduction to the Incheon Strategy states that it “will enable the Asian and Pacific region to track progress towards improving the quality of life, and the fulfilment of the rights, of the region’s 650 million persons with disabilities, most of whom live in poverty. The ESCAP secretariat is mandated to report every three years until the end of the Decade in 2022, on progress in the implementation of the Ministerial Declaration and the Incheon Strategy.”

India is an ESCAP member country and a participant of the Make the Right Real Campaign. The Indian government along with ESCAP held consultative meetings in March 2017 where participants included policy makers, statisticians and experts from across stakeholder ministries and government agencies including the Ministry of Social Justice and Empowerment (MOSJE), Ministry of Statistics and Programme Implementation (MOSPI), Ministry of Human Resource Development (MHRD), Ministry of Home Affairs (MHA), Ministry of Health and Family Welfare (MOHFW), National Commission for Women (NCW), National Commission for Protection of Child Rights (NCPCR), NITI Aayog and Disabled People’s Organisations (DPOs). The focus of these meetings was disability data collection, towards monitoring progress on implementing the Incheon Strategy.

India has ratified different international treaties, in particular the UNCRPD; this means that Indian laws and policies must reflect these ratifications.

106 MAKE THE RIGHT REAL!  
Retrieved from <http://www.maketherightreal.net/about-us>

107 MAKE THE RIGHT REAL!  
Incheon Strategy to “Make the Right Real” for Persons with Disabilities in Asia and the Pacific. Retrieved from <http://www.maketherightreal.net/incheon-strategy/>

## Indian Laws and Policies related to Disability

Two of the most important pieces of legislation to do with disability have been recently enacted in India. One is the Rights of Persons with Disabilities Act (RPD Act), 2016, and the other is the Mental Health Care Act, 2017.

### THE RIGHTS OF PERSONS WITH DISABILITIES ACT

To give a historical perspective, the Indian Lunacy Act of 1912 was replaced by The Mental Health Act 1987<sup>108</sup>, which was meant to address both mental illness and mental disability. However, in practice the 1987 Act ended up focussing only on mental illness. The Persons with Disabilities Act (PwDA), 1995 was the first legislation in the country that included people with different types of disabilities in its ambit. However, though it was a positive development in one sense, the PwDA was not viewed as one that adequately addressed the needs of people with disabilities; by recognising only seven disabilities and leaving out many including Autism from its purview, it was seen as having a limited scope and besides, not rights-based in its spirit.

On the other hand the new RPD Act 2016 that has replaced the PwDA, 1995 is more expansive and as Shabnam Aggarwal, founder Anandini says “steeped in the rights perspective”. The RPD Act 2016 begins by stating the intention “to give effect to the United Nations Convention on the Rights of Persons with Disabilities”. India had signed the UNCRPD and ratified it in 2007 but was laggard in the matter of legislative compliance to it. The new Act has taken almost ten years since then to take shape.

Disability activist Javed Abidi spoke of the RPD Bill before it was passed, as a game changer. Reflecting on it, he wrote:

The new law, when enacted, will repeal the old Disability Act, 1995, and usher the Indian disability movement into a new

<sup>108</sup> GOVERNMENT OF INDIA. The Mental Health Act. 1987. Retrieved from [http://wcdsc.ap.nic.in/documents/acts\\_dw/Mental\\_Health.pdf](http://wcdsc.ap.nic.in/documents/acts_dw/Mental_Health.pdf)

age, where disability itself will be defined based on an evolving and dynamic concept. It is hoped that the proposed new law, a robust rights-based legislation with a strong institutional mechanism, shall ensure enjoyment of rights by persons with disabilities on an equal basis with the non-disabled citizens of India.<sup>109</sup>

He pointed out the significance of the expanded scope of inclusions of disability groups in this Act, beyond the orthopaedically disabled, visually challenged and hearing impaired, to bring into its ambit many other groups, including persons with intellectual disability, autism, cerebral palsy, blood disorders and multiple sclerosis. (Refer to Appendix II for the list of 21 disabilities identified in the RPD Act.)

Though it took a long time for the Act to come to pass, Shampa Sengupta believes that it was worth the wait. In an online article, she says:

Finally, the Indian Government accepted the demands of activists for a new law, and in 2010 constituted a Committee under Dr. Sudha Kaul to draft it. There might be a large number of variations between the recommendations of the Sudha Kaul committee, and the bill actually passed in December 2016; however, the RPwD Bill is definitely going to bring major positive changes in the lives of millions of disabled people in our country.<sup>110</sup>

Shampa has been involved in several policy level interventions and is an Executive Committee member of the NPRD. The NPRD is closely involved with advocacy on multiple issues related to the implementation of the RPD Act 2016, taking up strongly the gaps and lacunae identified in the draft RPD Rules as well as the process by which these Rules were drafted by the government.

Shampa also points out in the article cited above:

Unfortunately, some in the disability sector don't see this law as a reason for celebration. There are some who feel that the law

109 ABIDI, J. (2016. December 5). The new disability law will be a game changer. Here's why. *The Hindustan times*. Retrieved from <http://www.hindustantimes.com/analysis/the-new-disability-law-will-be-a-game-changer-here-s-why/story-J5EPqir1CzNlnaGaP5bFNL.html>

110 SENGUPTA, S. (2016. December 20). The Rights of Persons with Disabilities Bill 2016 Is Historic, and Here's Why. *The Better India*. Retrieved from <http://www.thebetterindia.com/78948/why-rights-of-persons-with-disabilities-bill-worth-wait/>

should have been closer to the UNCRPD's spirit. There are even certain conflicting clauses in this law. For example, it says, 'The appropriate Government shall ensure that the persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and have the right to equal recognition everywhere as any other person before the law,' and yet it also talks about the provision of guardianship for certain kinds of disabled people, baffling lots of activists.

While the passage of this Act is a historical milestone in the country's disability rights movement there is continuing debate, discussion and argument over the legal provisions in it. For instance, Abha Khetarpal (disability rights activist and President of Cross the Hurdles, an NGO), expressed her reservations in a media report, saying:

There is a special mention about rights of women and children with disabilities, but nothing specific has been stated. There is no legal provision for women with disabilities in marriage or divorce laws, where we need more clarity because they suffer the most. As far as children with disabilities are concerned there is also a special mention, but we need clarity on how they are treated in institutions and inclusive education for them. In adoption laws too children with disabilities are left out. We need more specific provisions regarding adoption of children with disabilities.<sup>111</sup>

111 TNN. (2016. December 16). Activists term disability bill a 'skeptical Act. *Times of India*. Retrieved from <http://timesofindia.indiatimes.com/city/delhi/activists-term-disability-bill-a-skeptical-act/articleshow/56021997.cms>

The RPD Act in Chapter II, Section 4, makes a mention of Women and Children with disabilities in the following ways:

- (1) The appropriate Government and the local authorities shall take measures to ensure that the women and children with disabilities enjoy their rights equally with others.
- (2) The appropriate Government and local authorities shall ensure that all children with disabilities shall have right on an equal basis to freely express their views on all matters affecting them and provide them appropriate support keeping in view their age and disability.

These provisions are broad. They require public dialogue and advocacy and particularly self-advocacy platforms, to explore the scope of meaning and interpretation, to extend it to matters concerning sexuality and sexual and reproductive health and rights, to look at how to implement such provisions, as well as to consider the need for the training of government, administrative office bearers and service providers in alignment with the spirit and provisions of the law.

Chapter II, Section 9 deals with Home and Family, and says:

(1) No child with disability shall be separated from his or her parents on the ground of disability except on an order of competent court, if required, in the best interest of the child.

(2) Where the parents are unable to take care of a child with disability, the competent court shall place such child with his or her near relations, and failing that within the community in a family setting or in exceptional cases in shelter home run by the appropriate Government or non-governmental organisation, as may be required.

That the section dealing with home and family focuses only on a child with disability and home, family or alternative option for such a child, but does not mention other aspects of home and family, such as the right to home and family and to community support of a person with a disability who may be an adult; this appears to narrow the scope of provisions for home and family. This view is also held by the NPRD, as detailed in Appendix III. As mentioned above, dialogue and discussion are needed to explore the scope and interpretation of the section on home and family to include issues of sexual and reproductive health and rights, including for example, prevention of and protection from child sexual abuse.

Chapter II, Section 10, speaks of Reproductive Rights, stating:

(1) The appropriate Government shall ensure that persons with disabilities have access to appropriate information regarding reproductive(*sic*) and family planning.



(2) No person with disability shall be subject to any medical procedure which leads to infertility without his or her free and informed consent.

What exactly is ‘appropriate information’ and how one decides what is appropriate for whom, is left open to interpretation and may be subject to ignorance and bias based on personal value systems. This set of provisions appears to ignore the wide scope of reproductive health and rights, which includes a satisfying and safe sex life as well as the decision-making right, capacity and freedom to reproduce. It further seems to be silent on that aspect of reproductive rights that provides access to reproductive health care.

Shampa says, “RPD Act mentions gender in many places which is extremely positive outcome. It talks about reproductive rights but not about sexuality per se – even UNCRPD does not have any clause on sexuality. My question is do we really need laws on sexuality? Isn’t sexuality an intangible idea? Isn’t it better not to have any law on sexuality of disabled people?”<sup>112</sup>

112 Shampa Sengupta. 2017. Personal communication.

The more the conversations, the more diverse are the viewpoints that emerge. Nidhi Goyal, activist, trainer and researcher working in the field of disability rights and gender justice, is the founder and director of ‘Rising Flame’, and also currently works as a Programme Director at Point of View, researcher with Human Rights Watch and with CREA on international policy and advocacy. She considers the RPD Act a step forward from the PwD Act 1995, with regards to gender sensitivity and inclusion of sexual harassment and violence. However, as she says, it is not enough and there are some very problematic things in the act. She further adds that the rules are insufficiently framed and it is to be seen how implementation will be planned as the Act is positive but from the perspective of implementation it seems quite ambitious.

Nidhi reveals another problematic aspect of the Act. The Act, in the chapter on ‘Offences and Penalties’, Section 92 (f) states that whoever “performs, conducts or directs any medical procedure to be

performed on a woman with disability which leads to or is likely to lead to termination of pregnancy without her express consent except in cases where medical procedure for termination of pregnancy is done in severe cases of disability and with the opinion of a registered medical practitioner and also with the consent of the guardian of the woman with disability, shall be punishable with imprisonment for a term which shall not be less than six months but which may extend to five years and with fine.”<sup>113</sup> Nidhi points out that the Act does not define severe disabilities anywhere. Termination of pregnancy without consent in cases of severe disability, is a clampdown on reproductive choices of women with disability. She emphasizes that such a control is not exercised on any other woman under any other circumstances. As Nidhi says, “the law also reflects the perception of the larger society – that women with disability are child like, they don’t have a choice, their consent is not important, and they will be incapable of building a relationship or handling a child. It is a very dehumanizing attitude where women with disabilities are considered lesser than other women or not women enough particularly in cultural contexts where the identity of a woman is very closely build on the socially defined gender roles.” She observes that people assume that as non-disabled people, as policy makers with power and authority, they have the right to decide on behalf of women with disability.

There is criticism of both the process for drafting Rules and of the Rules themselves that have been drafted for implementation of this Act. A letter was sent in March 2017, from the NPRD to the Department of Empowerment of Persons with Disabilities of the MOSJE, and was also circulated amongst NGOs, activists and disability rights advocacy organisations. This letter points out lacunae in the Draft Rules and goes on to state:

We are given to understand that the Department is proposing framing of a policy for implementation of the Act. This is a fallacious line of thinking akin to putting the cart before the horse. While an Act should follow a policy, it cannot be the reverse. In any case, a policy cannot be merely confined

113 GOVERNMENT OF INDIA. Rights of Persons with Disabilities Act 2016. Retrieved from <http://www.disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf>

or restricted to implementation of a piece of legislation. A policy should ideally spell out of the overall approach of the government to a particular issue and its long-term perspective.... Additionally, the Committee constituted for the purpose of framing the rules has just three representatives from the disability sector. While we in [no] way want to cast aspersions on their capability, it goes without saying that the canvas has become much wider with the recognition of an additional 14 new conditions as disabling. Of the 21 disabilities now recognized, the committee has representation from just two.... It would therefore be in the fitness of things if consultations with stakeholders are held at both the state and national level where representatives from all the 21 conditions specified in the Act plus representatives of DPOs are invited and their inputs taken.<sup>114</sup>

114 From a copy of the letter dated 25<sup>th</sup> March 2017, sent by the National Platform for the Rights of the Disabled – received by email dated 25<sup>th</sup> March 2017

And Shampa Sengupta protested in an online post:

We saw that a Draft was uploaded in the Social Justice Ministry’s website on 6th of March and we were asked to send comments on it. This draft did not include a single one of our recommendations – it actually excluded all the Clauses on Gender aspect of the law as well as several other important clauses... our dismay turned into anger when we saw yet another set of Draft Rules uploaded in Ministry’s website on 10th March. Within a span of 1 week, there were two different drafts and this time, we were alarmed. A close scrutiny of both Government Drafts showed that every single mention of ‘private establishments’ which the RPD Act had mandated to be made accessible had been removed. A clear definition of ‘Neighbourhood schools’ and ‘Special Schools’ had been removed – it felt that as though the Education Chapter from RPD (Chapter III of RPD Act) did not exist. Also, there was no mention of chapters like Social Security, Health, Recreation etc. in any of the Government drafts... So, within three months of the RPD Act being passed, DPOs and disability groups are once again starting to agitate. And our struggle will go on.<sup>115</sup>

115 SENGUPTA, S. (2017. March 29). The Rights Of Persons With Disabilities Act Was Historical. But Its Implementation Ignored All Public Recommendations. *Feminism in India*. Retrieved from <https://feminisminindia.com/2017/03/29/rights-of-persons-with-disabilities-government-rules/>

The NPRD made suggestions to the Draft Rules to the RPD Act, 2016. Many of these address gender and sexuality issues. (Refer to Appendix III). These suggestions take into account the fact that issues of disability and sexuality emerge across the framework of laws protecting rights and addressing rights violations and therefore implementation of laws must look to the connections between them. However, these suggestions are not reflected in the final Rules, notified in June 2017.

## THE MENTAL HEALTH CARE ACT

The Mental Health Act was introduced in 1987 to repeal the Indian Lunacy Act, 1912.<sup>116</sup> The Mental Health 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.

The Mental Health Care (MHC) Bill of 2013 was drafted to replace the existing Mental Health Act of 1987. It was passed by the Rajya Sabha on 8<sup>th</sup> August 2016, but was only passed by the Lok Sabha in March 2017 and enacted on 7<sup>th</sup> April 2017. There was fierce dissent and debate surrounding this Act across multiple, differing viewpoints as reported in the media.<sup>117</sup>

Even while the bill was still before parliament and had not yet been enacted, a December 2014 report called ‘Treated Worse Than Animals’ by Human Rights Watch (HRW) stated:

Two bills currently before parliament, the Mental Health Bill and the Rights of Persons with Disabilities Bill, do not fully guarantee the rights of women with psychosocial or intellectual disabilities. Instead, they perpetuate institution-based care instead of shifting to a community-based model of services and support mandated by the disability rights treaty. [UN Convention on the Rights of Persons with Disabilities.]

116 GOVERNMENT OF INDIA. The Mental Health Act. 1987. Retrieved from [http://wcdsc.ap.nic.in/documents/acts\\_dw/Mental\\_Health.pdf](http://wcdsc.ap.nic.in/documents/acts_dw/Mental_Health.pdf)

117 PANDIT, S. (2017. April 08). Doctors divided on India’s new mental health bill. *Hindustan Times*. Retrieved from <http://www.hindustantimes.com/mumbai-news/doctors-divided-on-new-mental-health-bill/story-QO9T3htUdPZvA5fTqGLuYN.html> and CHATTERJEE, S. (2017. March 31). Psychiatrists: Mental health bill lacks focus on community care. *The Times of India*. Retrieved from <http://timesofindia.indiatimes.com/city/bengaluru/psychiatrists-mental-health-bill-lacks-focus-on-community-care/articleshow/57925979.cms>

The government should ensure that the bills protect the rights of women and girls with psychosocial or intellectual disabilities and promote adequate and accessible voluntary community-based services, in full compliance with the Convention on the Rights of Persons with Disabilities (CRPD), which India ratified in 2007.<sup>118</sup>

118 HUMAN RIGHTS WATCH. 2014. *Treated Worse than Animals: Abuses against Women and Girls with Psychosocial or Intellectual Disabilities in Institutions in India*. Retrieved from <https://www.hrw.org/report/2014/12/03/treated-worse-animals/abuses-against-women-and-girls-Psychosocial-or-intellectual>

The HRW report had also made the following recommendations about the then Mental Health Care Bill:

Only pass the Mental Health Care Bill after consulting with disabled persons' organisations and advocates representing persons with psychosocial disabilities and with at the very least the following amendments:

- Recognize the legal capacity of all persons with disabilities on an equal basis with others and the right to exercise it. Remove clauses that allow for plenary or limited guardianship, 'supported admission,' and a 'competency test' which could result in treatment without informed consent of the person concerned. Instead provide accommodations and access to support where necessary to exercise legal capacity.
- Ensure that advance directives cannot be overruled by mental health professionals, caregivers, or family members. Ban all forms of involuntary treatment, including electroconvulsive therapy, without the person's free and informed consent.
- Mandate a shift from institutional care to access to voluntary community-based mental health and other support services for people with psychosocial disabilities.
- Develop a time-bound plan to shift progressively towards providing access to voluntary community-based services for women and girls with intellectual or psychosocial disabilities, including adequate and appropriate education, mental health, and reproductive health services. Extend the District Mental Health Programme to all districts to ensure it

has sufficient resources and trained staff. Support efforts by nongovernment organisations, including disabled persons' organisations, to provide community-based services for persons with psychosocial or intellectual disabilities.<sup>119</sup>

119 Ibid

Commenting on the Bill prior to the enactment of this legislation, Shampa Sengupta wrote, "Now will the new Mental Health Care Bill bring in many changes? It is difficult to believe so; in general mental health care is a low priority for the government. Not only there's severe scarcity of trained persons to deal with the need of the sector, the stigma attached to mental health remains abundant in our society."<sup>120</sup>

One of the recommendations for legal reform and policy implementation made in the Human Rights Watch report in connection with the Rights of Persons with Disabilities Bill was, "Include all persons with disabilities under the bill, including persons with psychosocial disabilities, instead of covering them under the mental health law."

120 SENGUPTA, S. (2016. August 10). What does the Mental Health Care Bill mean for persons with mental illness? *Feminism in India*. Retrieved from <https://feminismindia.com/2016/08/10/mental-health-care-bill-2013/>

This recommendation was not taken and Amba Salelkar, a lawyer with the Equals Centre for Promotion of Social Justice who focuses on harmonisation of law and policy with the UNCRPD, has written about this as well as other contradictions between the goals and provisions of the Mental Health Care Act 2017:

The first indication of such a contradiction is the enactment of a separate mental health law despite the enactment of the Rights of Persons with Disabilities Act in 2016. There is a need to protect the rights of persons with psychosocial disabilities, as they are prone to abuse and exploitation in the name of treatment. These safeguards could easily be brought within the ambit of mainstream legislations relating to health, disability rights, or even criminal law. But this is not the norm because of the common misconception that a person with a psychosocial disability would always, without cause, be resistant to treatment, and therefore coercive measures must

121 SALELKAR, A. 2017. How The Celebrated Mental Healthcare Act Restricts Individual Liberty And Fails To Comply With International Standards. *The Caravan*. Retrieved from <http://www.caravanmagazine.in/vantage/mental-healthcare-act-restricts-individual-liberty-fails-international-standards>

be undertaken for the treatment. As a result, mental-health laws tend to create exceptions to the rights found in health and disability laws, such as the necessity for informed consent – or any consent – to medical treatment.<sup>121</sup>

Further ahead, Amba writes:

In reality, persons with disabilities may require different degrees of support on different issues. Chapter V of the act, which deals with the rights of a person with psychosocial disability, does not speak about the right to support in making their decisions. Bringing the right to support within the ambit of the act would entail a detailed and costly exercise of working out individual support plans for persons who require the same. Various legal formulations are being attempted, world over, to give effect to these rights. The latest report of the UN Special Rapporteur on the Rights of Persons with Disabilities unpacks the obligation of the state to provide support, as opposed to care, to persons with disabilities, and clearly links the lack of support to eventual institutionalisation. It also requires that states must establish an immediate moratorium on new admissions to institutions and set up a policy framework to guide deinstitutionalisation processes including the development of adequate community support for persons with disabilities in decision-making.

In an online article, while pointing out some shortcomings of the Mental Health Care Bill, journalist Divya Srivastava also commended some aspects of it, including the one on advance directives, saying:

... the most remarkable feature of this bill is the introduction of advance directives – this gives people suffering from a mental illness the right to choose their mode of treatment, and by nominating representatives who will ensure that their choices are carried out. Giving people diagnosed with a mental illness the freedom to choose conveys a strong message to the masses that suffering from a mental disorder does not rob an individual of decision-making capacities. It instils in the citizens that

everyone, even those diagnosed with a mental illness, are entitled to a life of dignity, and they must not have to live in isolation, away from their families or the community, at large.<sup>122</sup>

Yet, however as Amba points out, “Section 11 of the act empowers a mental-healthcare professional, a caregiver or a nominated representative to make an application to the Mental Health Review Board seeking to set the advance directive aside. The board may then take a decision to ‘review, alter, modify or cancel the advance directive.’”<sup>123</sup> A relative or a care provider may initiate this process and depending on the intent and power held or assumed by this person, there is scope for abuse of the individual who comes under the purview of this legislation. This directly impacts women and those who may identify as LGBT.

Another provision of the Act that is problematic is Section 4 on determining decision-making capacity (the competency test that the HRW Report had also recommended be removed). As Amba explains in the article:

Section 4 of the Mental Healthcare Act provides that a mental-health professional – which includes a clinical psychologist, mental-health nurse, or a psychiatric social worker – may determine whether a person has the capacity to make mental healthcare and treatment decisions. To determine whether a person can make decisions about their own healthcare, the act requires that such a person must have the ability to understand the relevant information to take decisions regarding their treatment and mental healthcare, appreciate the consequences of the decision, and communicate the decision. This method of determining an individual’s capacity for self-determination, also known as the two-stage functional test for capacity, was specifically termed as a denial of “a core human right” by the Committee on the Rights of Persons with Disabilities the treaty body of the CRPD, which comprises a body of experts responsible for monitoring its implementation.

122 SRIVASTAVA, D. (2017. January 6). Mental Health Care Bill: A much-needed reform that still has a long way to go. *Firstpost*. Retrieved from <http://www.firstpost.com/india/mental-health-care-bill-a-much-needed-reform-that-still-has-a-long-way-to-go-2952636.html>

123 SALELKAR, A. 2017. Mental Healthcare Act Restricts Individual Liberty. *The Caravan*. Retrieved from <http://www.caravanmagazine.in/vantage/mental-healthcare-act-restricts-individual-liberty-fails-international-standards>



It is important to understand that persons with disabilities have the right to equal recognition before the law and that they may require support to exercise this right. This requires awareness of the distinction between caring for someone, or doing and deciding for them, or providing support of varying degrees, as may be required to enable a person to exercise their rights and choices for themselves. While it is not within the scope of this paper to do justice to these and other debates and points of view, it is crucial to underline that living with mental illness or psychosocial disability continues to be intensely stigmatised and misunderstood, not only across various sections of society, health and development professionals, including frontline workers, but also the experts who drafted the Mental Health Care Bill.

The Mental Health Care Act, 2017, makes specific provisions that have significant implications on about issues of sexuality and psychosocial disability. We are highlighting some of these provisions and their possible implications below:

Section 3 (3) - Mental illness of a person shall not be determined on the basis of,

(a) political, economic or social status or membership of a cultural, racial or religious group, or for any other reason not directly relevant to mental health status of the person;

(b) non-conformity with moral, social, cultural, work or political values or religious beliefs prevailing in a person's community.

It is important to explore the ambit of concepts of membership of a cultural group, and of non-conformity, to extend these to issues of gender and sexual identity. As Bhargavi Davar points out, "Systems also view men and women very differently. Any deviation from their expected roles for women increases their chances of being diagnosed with mental illnesses, of ending up in an institution and staying there. This does not happen to men."<sup>124</sup>

124 SHRUTI, S. (2016. November 11). In Conversation With Bhargavi Davar. *Feminism in India*. Available at <https://feminisinindia.com/2016/11/11/interview-bhargavi-davar-mental-health-activist/>

Section 18, (2) - The right to access mental healthcare and treatment shall mean mental health services of affordable cost, of good quality,

available in sufficient quantity, accessible geographically, without discrimination on the basis of gender, sex, sexual orientation, religion, culture, caste, social or political beliefs, class, disability or any other basis and provided in a manner that is acceptable to persons with mental illness and their families and care-givers.

Sexual orientation is a term that is not found often in Indian laws and policies but has received particular mention in the new Mental Health Care Act, 2017.

The term sexual orientation articulated in this Act is significant for different reasons. For one, it is legal acknowledgement and acceptance of the fact that there is such an issue individuals may grapple with in India, and that it may lead to rights violations. This stands as opposed to the oft heard, politically promoted viewpoint, that issues of sexuality such as these, are not a part of our society and culture. Further, it is important to note, especially as India is in the midst of a long drawn series of sexuality and rights advocacy initiatives, political conflict and legal processes around Section 377 of the Indian Penal Code (that criminalises same-sex sexual activity).<sup>125</sup> The Delhi High Court had read down this section in a 2009 judgement, meaning that adult, private consensual same-sex sexual activity was no longer a crime. Unfortunately, in 2013 the Supreme Court reversed the High Court verdict.<sup>126</sup>

Bhargavi Davar has worked extensively on issues of the inclusion in community, of persons with psychosocial disabilities and on models of support that are rooted in community and social systems. Her frame of work is in the human rights context and she speaks of continuing conversations on human rights violations across meetings and advocacy efforts, “particularly violations of the rights of gay people and people who are transgender. They come under the purview of psychiatric systems of care, particularly gay men, young people dealing with identity and sexual orientation, gay people who also have a physical or psychosocial disability”.<sup>127</sup>

Bhargavi Davar believes that social problems such as hostility

<sup>125</sup> GOVERNMENT OF INDIA. Section 377 in The Indian Penal Code. Unnatural offences. Whoever voluntarily has carnal intercourse against the order of nature with any man, woman or animal, shall be punished with [imprisonment for life], or with imprisonment of either description for a term which may extend to ten years, and shall also be liable to fine. Explanation: Penetration is sufficient to constitute the carnal intercourse necessary to the offence described in this section. Retrieved from <http://www.advocatekhaj.com/library/bareacts/indianpenalcode/377.php?Title=Indian%20Penal%20Code,%20186o&STitle=Unnatural%20offences>.

<sup>126</sup> Downloadable copy of the Supreme Court judgment Retrieved from <http://www.lawyerscollective.org/wp-content/uploads/2013/12/naz-foundation-SC.pdf>

<sup>127</sup> Bhargavi Davar. 2017. Personal communication.

towards young people grappling with sexuality and sexual identity are medicalised and human rights violations are caused by this over-medicalised perspective, with the practice of procedures such as shock treatments and aversion therapy. She elaborates, “The Diagnostic and Statistical Manual (DSM) is so constructed that though being gay is not a mental disorder, people can be brought in through mental disorder interpretations of distress. In India, for people going through sex transitions, capacity to consent is a vulnerable area with gate keeping by psychiatrists. This is a major area of trouble.”

Section 20 (2) of the MHC Act states that every person with mental illness shall be protected from cruel, inhuman or degrading treatment in any mental health establishment and shall have the following rights, namely:

- (a) to live in safe and hygienic environment;
- (b) to have adequate sanitary conditions;
- (c) to have reasonable facilities for leisure, recreation, education and religious practices;
- (d) to privacy;
- (e) for proper clothing so as to protect such person from exposure of his body to maintain his dignity;
- (f) to not be forced to undertake work in a mental health establishment and to receive appropriate remuneration for work when undertaken;
- (g) to have adequate provision for preparing for living in the community;
- (h) to have adequate provision for wholesome food, sanitation, space and access to articles of personal hygiene, in particular, women’s personal hygiene be adequately addressed by providing access to items that may be required during menstruation;
- (k) to be protected from all forms of physical, verbal, emotional and sexual abuse.

This section and its provisions do particularly deal with some SRHR issues that have been raised repeatedly by mental health activists and rights advocates. Implementation of these provisions is another issue entirely as concepts such as adequate sanitary conditions, privacy and proper clothing are all open to interpretation.

The reality is that most mental health establishments run by the state are over-crowded and the sheer weight of numbers is overwhelming. While the Mental Health Care Bill was still being considered and had not yet been passed, the HRW Report had described the condition of over-crowding:

For example, as of November 2014, Asha Kiran or Avantika, a government institution for persons with intellectual disabilities in Delhi, is home to just under 900 people, nearly three times its capacity. At Pune Mental Hospital, Dr. Vilas Bhailume, the hospital's superintendent, told Human Rights Watch that there were just 25 working toilets for more than 1,850 patients. "Open defecation is the norm," he said. Researchers found that lice were rampant in most state-run institutions visited: during interviews at 10 government institutions, women and girls constantly pulled lice from their hair. Instead of providing medicated shampoos and improving hygiene, many women were forcibly shaved, further humiliating them. Ameena, a 40-year-old woman with schizophrenia described receiving soap just once a week, on a Friday. "We don't even get towels. We brush our teeth with tooth powder using our fingers. We change clothes every two days and have to stay naked while the laundry is being done," she said.<sup>128</sup>

128 HUMAN RIGHTS WATCH.  
2014. Treated Worse than  
Animals.

The Human Rights Watch team also reported that they had spoken to over 50 women and girls with intellectual and psychosocial disabilities who were at the time being kept in institutions without their consent, and who asked to be taken away from these institutions. These are gross violations of human rights.

Whether the provisions of the Mental Health Care Act 2017 will

translate into positive implementation that protects the individual from violations of their human rights is a matter of urgent concern.

Finally, as pointed out in *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*:

While the Act has a whole chapter (Chapter V) that deals with rights of persons with mental illnesses, most of these are related to the broader right to (quality, affordable, accessible, dignified) mental healthcare services. There is mention of non-discrimination on the grounds of sex, gender and sexual orientation in mental healthcare services as well as protection of persons with mental illness from violence and abuse. However, there is no mention in this Act about sexual rights or sexual health services and its link with health and well-being.<sup>129</sup>

129 RANADE, Ketki, and ANJALI—MENTAL HEALTH RIGHTS ORGANISATION. *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*. Kuala Lumpur: Asian-Pacific Resource & Research Centre for Women (ARROW), 2017. Retrieved from <http://arrow.org.my/publication/sexual-rights-women-psychosocial-disabilities-india/>

130 GOVERNMENT OF INDIA. POCSO Act 2012. (Section(s) 5 and 9), Retrieved from <http://indiacode.nic.in/amendmentacts2012/The%20Protection%20of%20Children%20From%20Sexual%20Offences%20Act.pdf>

In 2012, **The Protection of Children from Sexual Offences Act**, (POCSO 2012) came into force.<sup>130</sup> This legislation has stringent provisions that include detailing the circumstances and clauses that comprise aggravated penetrative sexual assault and aggravated sexual assault, and includes in such assault that which causes grievous hurt, bodily harm, incapacitation, mental illness, pregnancy or life threatening infection such as HIV, and makes specific reference in these provisions to a child who has a physical or mental disability. Implementation of POCSO 2012 continues to be challenging on many fronts. In the December 2015 article, ‘The Pocso Act: A Quick Review’, Srishti Agnihotri and Minakshi Das have spoken of the implementation of POCSO as “mired in malpractices and outdated legal proceedings”. Their three-pronged analysis covers legislative, judicial and administrative aspects and comes to the conclusion that “the progress report of the POCSO Act gives mixed results. While the mandate of the legislation is truly radical in that it aims to protect children against sexual abuse, and provides for a victim sensitive criminal justice process, there are several snags in its implementation.”

**The Criminal Law Amendment Act 2013** specifies detailed descriptions, provisions and punishments for sexual offences, including punishments for whoever “commits rape on a woman suffering from mental or physical disability”.<sup>131</sup> This legislation itself was the result of public national and international outrage at the brutal gang rape of a young woman, Jyoti Singh, on a bus in New Delhi, on 16th December 2012, resulting in her death a few days later. This incident caused widespread shock, condemnation and debate, leading to the setting up of a judicial committee headed by the former Chief Justice of India, JS Verma, to report on the incident, the state of the laws and enforcement, as well as suggest amendments to the laws dealing with sexual offences.<sup>132</sup>

For a 2013 article, R. Dawn from the Department of Education, Loreto College, Kolkata, undertook a review of literature, articles and government documents specifically to study sexual assault of women with disabilities and the loopholes in the law in India. In the Abstract of her article, she states:

In India, women with disabilities need to be provided with adequate knowledge about sexuality which will equip them to understand that they have been sexually assaulted. There is the need for policy makers to ensure greater accessibility to complaint and redressal mechanisms for women with disabilities. Efforts need to be made to strengthen the legal system and necessary legal aid/help to bring the perpetrators of such crime to justice has to be provided.<sup>133</sup>

**The Rehabilitation Council Act of India, 1992** is considered to be another important legislation with respect to people with disabilities.<sup>134</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. This Act was amended in 2000.<sup>135</sup> A review of the Act shows that there are no provisions from the perspective of

131 GOVERNMENT OF INDIA. Criminal Law Amendment Act, 2013. (Section 376 (2) I) Retrieved from <http://indiacode.nic.in/acts-in-pdf/132013.pdf>

132 Report of the Committee on Amendments to Criminal Law. Retrieved from <http://www.prsindia.org/uploads/media/Justice%20verma%20committee/js%20verma%20committee%20report.pdf>

133 DAWN, R. (2013) Our lives, our identity”: women with disabilities in India. *Disability and Rehabilitation*. Vol. 36. Iss. 21. 2014. Abstract Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/24369102>

134 GOVERNMENT OF INDIA. Rehabilitation Council of India Act. 1992. Retrieved from <http://www.advocatekhaj.com/library/bareacts/rehabilitationcouncil/index.php?Title=Rehabilitation%20Council%20of%20India%20Act,%201992>

135 GOVERNMENT OF INDIA. RCI Act, Amendment 2000. Retrieved from <http://www.rehabcouncil.nic.in/forms/Sublink2.aspx?lid=842>

sexual and reproductive health and rights or any other social aspects of the lives of people with disabilities.

**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 PwDA, 1995.<sup>136</sup> 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.

136 GOVERNMENT OF INDIA. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Mental Disabilities Act. 1999. Retrieved from <http://www.thenationaltrust.gov.in/upload/uploadfiles/files/act-englsih.pdf>

The National Trust Rules 2000, under the provisions of Section 17 specifying procedure for removal of guardians mentions sexual abuse in sub-section (vi) (d) as one of the elements constituting abuse or neglect. This is the only direct reference to sexuality in any context in the Act, Rules or Regulations.

In the National Trust Regulations of 2001, there is reference to male-female and gender restrictions on guardianship applications such that Section 12 (7) states that no single male can be guardian to a female ward and in the case of a female ward, the male guardian is a co-guardian along with spouse who is referred to as ‘master co-guardian’.

The Act itself has broad provisions related to empowerment and independent living and thus can be expanded to cover 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. However, the National Trust Act will need to be reviewed in light of both the provisions of the UNCRPD and the new RPD Act of 2016.

Shampa Sengupta points out one of the areas of exploration across the two Acts, the National Trust Act and the RPD Act, in an online piece focusing on the RPD when the Bill was passed by both

houses of Parliament in December 2016. She focuses on the issue of guardianship and while explaining the areas of debate caused by the provisions of the RPD Act, she also says, “Perhaps it is important to read this law in conjunction with another law – namely the National Trust Act – under which guardianship has been mandated till date.”<sup>137</sup>

There are several other laws and policies that address aspects of sexuality directly and indirectly. Some of them are listed in Appendix IV. They do not directly refer to issues of disability but it would be useful to examine how they might be applied. 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.

137 SENGUPTA, S. (2016, December 20). MY VIEW: The Rights of Persons with Disabilities Bill 2016 Is Historic, and Here’s Why . *The Better India*. Retrieved from <https://www.thebetterindia.com/78948/why-rights-of-persons-with-disabilities-bill-worth-wait/>

## 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). Despite two enabling legislations, as well as two Five Year Plans, progress was slow.

A significant achievement during the Tenth Plan was the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by the Government of India in 2007.



The Eleventh Five Year Plan of 2007 to 2012, adopted the term ‘inclusive growth’ to describe the approach and strategy behind the plan. The Plan document stated in its preface, “The objective of inclusiveness is reflected in the adoption of 26 other monitorable targets at the national level relating to (i) income and poverty, (ii) education, (iii) health, (iv) women and children, (v) infrastructure, and (vi) environment.”<sup>138</sup>

138 GOVERNMENT OF INDIA. PLANNING COMMISSION. 2008. Eleventh Five Year Plan. (2007–2012). Inclusive Growth. Retrieved from [http://planningcommission.nic.in/plans/planrel/fiveyr/11th/11\\_v1/11th\\_vol1.pdf](http://planningcommission.nic.in/plans/planrel/fiveyr/11th/11_v1/11th_vol1.pdf)

The document speaks of persons with disabilities in chapter 6, under section 6.171: “This section deals with certain other groups that suffer social and economic handicaps which must be addressed to ensure to them equality of economic opportunity and equal access to services by the State. Steps are also needed to prevent social discrimination against them.” Words and concepts such as empowerment, economic potential, assistance, training, productive contributors, multi-pronged cross-sectoral approach, universal design and barrier-free environment found their way into the text; a gender perspective, reproductive and sexual health and rights did not.

The approach note of 2011 to the Twelfth Five Year Plan of 2012 to 2017, is titled ‘Faster, Sustainable and More Inclusive Growth.’ The 2013 document detailing the plan across three volumes includes disability in Volume 3, Social Sectors. The chapter on Health states at the very beginning, “The determinants of good health are: access to various types of health services and an individual’s lifestyle choices, personal, family and social relationships. The latter are outside the scope of this Chapter. The focus in this Chapter is on the strategy to deliver preventive, curative and public health services.”<sup>139</sup>

139 GOVERNMENT OF INDIA. PLANNING COMMISSION. Twelfth Five Year Plan. (2012–2017). Social Sectors. Volume III. 2013. Retrieved from [http://planningcommission.nic.in/plans/planrel/fiveyr/12th/pdf/12fyp\\_vol3.pdf](http://planningcommission.nic.in/plans/planrel/fiveyr/12th/pdf/12fyp_vol3.pdf)

This seems to take a restrictive view of health, with personal, family and social relationships as determinants of health excluded from discussion in the development plan. Further along in this chapter in a section on inclusive agenda for health, a description of barriers to access to services makes a mention of gender sensitivity and child friendliness. There is also mention of accessible information for the visually impaired, of information for caregivers, and of facilities in

hospitals for the hearing impaired. These inclusive agenda points do not find reflection in the health outcome goals in the outcome indicators section of the chapter. Chapter 23 on ‘Women’s agency and Child Rights’ specifically states:

The ending of gender based inequities, discrimination and violence is an overriding priority in the Twelfth Plan. Ending gender based violence against girls and women including improvement in the adverse and steeply declining child sex ratio, is therefore, recognized as an overarching monitorable target of the Twelfth Plan for Women and Children. The 12th Plan will endeavour to provide nurturing, protective and safe environment for women to facilitate their entry into public spaces.<sup>140</sup>

140 Ibid.

Further, of six points of the strategy focusing on women’s agency, point (v) is “Inclusiveness of all categories of vulnerable women”. Section 23.58 within this chapter is titled ‘Differently abled women’. It is a small section that primarily speaks of enabling infrastructure in educational institutions and spaces of vocational training, along with sensitisation of staff and government run short stay facilities. It states, “The Twelfth Plan will endeavour to engender all programmes aimed at the differently-abled.”

The articulation of concept and approach in these plan documents shows perceptible change in the direction of using rights based language. A study of fund allocation and utilization for disability and health related issues would be useful for advocacy and research efforts. The scope of intent and coverage of development documents such as these is vast and it is not within the purview of this paper to conduct in-depth analysis of them. Some of them have been highlighted above for the purpose of thought and further exploration using the lens of sexuality and disability rights.

As of 2017, there will be no more Five Year Plans as the system is being changed and the concept of a 15-year vision is being explored by the National Institution for Transforming India (NITI) Aayog,

141 NAIR, R. & SOOD, J. (2016. May 14). NITI Aayog to replace 5-year plans with 15-year vision document. *Live Mint*. Retrieved from <http://www.livemint.com/Politics/6ysYTG3yy9lSo6mzKRhmK/Niti-Aayog-to-replace-5year-plans-with-15year-vision-docum.html>

142 SHARMA, Y. (2017. April 24). Niti Aayog's governing body begins deliberations on 'Vision Document', *Economic Times*. Retrieved from <http://economictimes.indiatimes.com/news/economy/policy/niti-aayogs-governing-body-begins-deliberations-on-vision-document/articleshow/58325602.cms> and  
PTI. (2017. April 23). With PM Modi and Team India, Niti Aayog meeting on 'Vision Document' begins. *Hindustan Times*. Retrieved from <http://www.hindustantimes.com/india-news/with-pm-modi-and-team-india-niti-aayog-meeting-on-vision-document-begins/story-86p1p22XROEAoK3o4nazM.html> and  
PTI. (2017. April 23). Niti Aayog Brainstorms Over Long-Term Vision Document. *NDTV Profit*. Retrieved from <http://profit.ndtv.com/news/economic-policy/article-niti-aayog-brainstorms-over-long-term-vision-document-1684865>

which replaced the Planning Commission in 2015. As reported, the vision document is to be supported by a seven year National Development Agenda detailing programmes and schemes.<sup>141</sup> As of April 2017, there have been a few media reports of the beginning of deliberations on this document.<sup>142</sup> At the time of updating this paper, we have not been able to find any information regarding the provisions and content of this vision document.

# 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 is important to learn from people with disabilities themselves and from their care providers about the challenges the former face with respect to expressing their sexuality as well as accessing sexuality and sexual and reproductive health information and services.

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. In an online article for In Plainspeak, Dinesh Gupta, who is a person with cerebral palsy, wrote:

My desire for sexual intimacy may sound weird to many people but this is my reality. I do not want to live only with my parents throughout my life. I want to be independent and also desire a special person to share the joys and sorrows of my life with, or talk about the mental asylum in our minds that is often created from stress and 'physical' fatigue. I would like to get married and have a sexual life, but my parents do not feel that I should get married. I have tried to bring it up with them, but they are very resistant to the idea. Sexual relationships outside of marriage are still taboo in our society. And, even if they

143 GUPTA, D. 2009. I Column. *In Plainspeak*, TARSHI. Issue 1, 2009.

were okay, there are very few social spaces for people with disabilities to meet and have intimate relationships.<sup>143</sup>

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. Parents and care providers of people with disabilities have been approaching TARSHI for almost two decades now for inputs by way of information or sessions and workshops in schools and institutions for children and young adults with disabilities. This initially used to happen only when there were 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. Speaking of the experience of offering a workshop on sexuality and intimacy for visually impaired participants in 2012, Sushmita Bubna, founder-director of the NGO Voice Vision said, "Sex is still a taboo in India. So when we mailed people with the invitation, they were very happy with the idea of the workshop, but were hesitant to attend."<sup>144</sup>

144 DNA. (2012. August 27). Sex Education for Visually Impaired. Retrieved from <http://www.dnaindia.com/mumbai/report-sex-education-for-visually-impaired-1733148>

According to Nidhi Goyal, "Issues of sexual and reproductive health and rights for persons with disabilities and especially girls and women with disabilities is seen as something which is superfluous at best and a complete non-issue at worst within the disability sector too." Speaking of her own experience, she states, "When I had acquired my visual impairment during my teenage year, I was enraged at the inaccessibility and unsupportive educational, infrastructural, professional and social environment in Mumbai. Gifted with an indomitable spirit and with terrific family support, I moved ahead, extremely conscious of the fact that this support was missing for many other people like me, and with a vow to create this support for them."<sup>145</sup>

145 DUTT, A. 2015. Interview: Nidhi Goyal. *In Plainspeak*, TARSHI. Retrieved from <http://www.tarshi.net/inplainspeak/nidhi-goyal/>

Nidhi has indeed gone ahead and created programmes on sexuality information and education for people with disabilities. However she has also found that organisations and institutions that may be assumed to be sensitive and supportive towards their service users may unwittingly present barriers to girls and women independently thinking and processing SRHR issues in their own lives. Nidhi has recently written of her experiences and observations conducting sexuality and disability workshops of Point of View<sup>146</sup> with women with visual impairments. Speaking of institutional gate keeping, she gives the example of a workshop where:

During a role play exercise about intimate partner violence, when the trainer asked what the women participants would do in an abusive situation, the organisation's head intervened and said, 'You will not bear it, right? Of course, we are strong, so no taking nonsense from anyone.' This was met with some silence and some acceptance, which seemed forced. The space to differ, to express doubts on how to leave a violent situation, to puzzle over the contexts of the women and their own beliefs, was basically choked.<sup>147</sup>

Cultural norms and social conditioning of many participants manifest as barriers to accessing educational and informational resources made available at platforms such as Nidhi's workshops. She writes, in the same article quoted above:

There was immense resistance by at least one participant in every workshop to touch the tactile body models, particularly the penis model, and to touch the condom or take part in the hands-on demonstration. In a workshop in Ahmedabad, one of the girls started chanting her god's name before she could take the decision to touch the model penis and in a second workshop in Ahmedabad with girls of a similar age and demographic background, three girls refused because they argued it was against their religion as Muslims. In Nagpur, one girl left the class, refusing to participate in the condom demonstration, and in several instances in Mumbai and Pune some exhibited extreme discomfort before giving in to peer

146 POINT OF VIEW. Workshops – Sexuality and Disability. Retrieved from <http://workshop.sexualityanddisability.org>

147 GOYAL, N. 2017. Denial of sexual rights: insights from lives of women with visual impairment in India. *Reproductive Health Matters* Vol. 25, 2017 - Issue 50: Disability and sexuality: claiming sexual and reproductive rights. Retrieved from <http://www.tandfonline.com/doi/full/10.1080/09688080.2017.1338492>

pressure or excitement and agreeing. Although the number of participants with extreme negative reaction was small, they were nonetheless present. In three workshops, participants argued against or showed their reluctance or irritation at accepting teaching about sex or positive sexuality, although they were ready to talk about rape or sexual violence. In one workshop, half the girls refused to participate and turned their backs on the trainer, and in two others they were vocal about their displeasure on the subject of sexuality and sex.

The fact is that this is not surprising given that comprehensive sexuality education is not offered to young people and that staff in many organisations that work on the ground are themselves not trained to talk about these issues. Working with service users and clients on disability issues, without knowledge of the connection with sexuality, presents its own set of problems for organisations. According to Bhargavi Davar, “A big challenge is in the area of training resources, to equip programme staff to deal with sexuality issues or undertake sexuality education with programme communities.” Speaking of a specific case involving sexual abuse that brought this point home to the Bapu Trust staff some years ago, she refers to the inability of the professional psychologist to identify the abuse or impact of abuse.<sup>148</sup>

148 ALEYA, S. 2015. Of Rabbits, Monsters and Terrified Therapists. *In Plainspeak*, TARSHI. Retrieved from <http://www.tarshi.net/inplainspeak/rabbits-monsters-and-terrified-therapists/>

149 CREA, ANJALI MENTAL HEALTH RIGHTS ORGANISATION, POINT OF VIEW, EQUALS CENTRE FOR PROMOTION OF SOCIAL JUSTICE and SRUTI DISABILITY RIGHTS CENTRE *Needs Assessment Report- Addressing Disability and Sexuality Rights, Closing the Gap – Building Institutional Capacity to Address Sexuality and Disability. (2016) (Unpublished Draft)*

Similarly, in the CREA survey, of the 27 organisations interviewed, only one organisation mentioned working on sexuality and reproductive health. The report states, “Though most other organisations did feel it was important to work on sexuality and reproductive health, they had not made any concerted efforts to include it in their work. One of the major reasons cited was that they didn’t have the skill and the trainers who could comfortably train.”<sup>149</sup>

The next section explores 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 ‘non-sexual’ or ‘oversexed’. Shampa Sengupta shared a report of a workshop with parents at a Kolkata school where “A parent was quick to respond saying that disabled people do not hesitate in exploring their sexuality whereas a non-disabled person could be inhibited.”<sup>150</sup> The use of the word ‘inhibited’ provides an understanding of sexuality and disability that takes into account the issue of socialisation and the lessons many children learn from family and society around them. To shed inhibition is often seen as a positive effort leading to creative self-development in an individual. However, if an individual has an impairment or disability, we find it challenging to deal with the lack of inhibition that we associate with lack of capacity caused by the impairment or disability.

150 Shampa Sengupta. 2017.  
Personal communication.

In the 2017 paper, *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*, the authors note:

In the context of persons living with mental illness, some of the stereotypes include hyper-sexuality, promiscuity, disinhibition, and inappropriate sexual expression. Linked to these is the idea that persons diagnosed with mental illness lack capacity for rational judgment/decision-making. These attitudes lead to practices such as being denied any kind of privacy, including



having no private space for sexual stimulation, masturbation, or space to be able to have sex with a partner, and surveillance of behaviours within the home as well as outside. For instance, rules related to use of the phone, internet, social interactions, who, when, how long to meet, how often, where and so on. The surveillance and control of people with disabilities, possibly by well-meaning care providers, is common within families and homes as well as institutions. This surveillance and shaming or damning messages are heightened for women with psychosocial disability and often lead to internalisation of sex negative and body-negative ideas.<sup>151</sup>

151 RANADE, Ketki, and ANJALI—MENTAL HEALTH RIGHTS ORGANISATION. *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*. Kuala Lumpur: Asian-Pacific Resource & Research Centre for Women (ARROW), 2017. Retrieved from <http://arrow.org.my/publication/sexual-rights-women-psychosocial-disabilities-india/>

Society largely considers individuals with disabilities unattractive and therefore incapable of being in sexual or intimate relationships. People with disabilities are looked upon with pity and considered to be undesirable, especially sexually. Societal attitudes that define the individual with disability by their disability alone fail to acknowledge the person as a whole. The same view further leads to the belief that people with disabilities are not sexually assaulted or abused as no one will desire them. It is also falsely assumed that all people with disabilities are incapable of engaging in any sexual activity, or of being sexually intimate.

The consequence is that there is a severe lack of accessible resources and support for persons with disabilities. Given that rights based comprehensive sexuality education resources are difficult to create and to access even for non-disabled people due to factors such as age, internet access, insufficient or no focus in school and educational curriculum, socio-cultural norms, gender and other such, the situation is even more constricting for persons with disabilities who may often be dependent on others for their access to and understanding of these issues.

Girls and women with disabilities who are seen as non-sexual and unmarried are 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, or, as Sameera Shamim adds here, “Information which may give language to their desires and aspiration. There are also multiple instances where girls with disabilities are abused within the family and often mothers are aware of the abuse. However, no mention is made of the same as it would lead to further abuse or restrictions for the girl. So the girl with disability is protected from the outside world, controlled by lack of information or access to interaction with others, and is often found to be abused within the so called safe haven of the home.”

In this context, it is worth considering the impact of double self-stigmatisation where, being a person with a disability who is also questioning or focusing on sexuality, the individual feels unable to discuss or find acknowledgement of their thoughts and feelings. The impact of this, on women in particular, is well described in the documentation of the Kolkata workshop shared by Shampa: “... a disabled body is thought of as outside the domain of a desiring or desired body. This culturally constructed attitude adversely impacts the self confidence and body image of a disabled woman most. Societal attitudes do not acknowledge that she can have desires. She is made to feel ashamed of her disability and it is assumed that she would always think of herself as ‘ugly’. Therefore, she is supposed to lack agency in thinking of herself as beautiful or attractive. She is not supposed to dress up. She is not supposed to be like any other non-disabled woman who can marry or give birth to children. Society would like to imagine that a disabled woman can neither menstruate nor ovulate! The effect of such attitude is that disabled women feel all the more isolated and marginalized. They start internalizing these negative perceptions about themselves and cannot develop any self-esteem. It is this negative attitude about themselves and their bodies that become the biggest barriers to exploring their sexual selves. Moreover, the presumption that disabled individuals are asexual further creates a barrier to empowering disabled people with knowledge about sexuality.”<sup>152</sup>

Parents and care providers play a crucial role in matters of sexuality and self-concept, particularly in the lives of children and young people. The FST study found that:

Issues concerning safety and violence were discussed by 63% parents with their child with disability. Majority i.e., 93% of the parents were aware that their child with disability also underwent bodily changes as they grew up and had physical and emotional requirements just like their able bodied child. Furthermore, 76% of the parents reported observing their child with disability looking at the mirror for long durations and smiling or giggling at self. More than half of the respondents (51%) did not want to address the issue of body self-exploration at all and did not respond to the question. This speaks of the urgent need to expand awareness and sensitization work with families of children with disabilities. Of the remaining (20 respondents) who did respond, 40% of the parents discussed “the incident of seeing their child exploring themselves” with their child. 25% of those who responded to this question admitted scolding their children when they found them exploring their bodies.

Such an approach is likely to negatively affect many aspects of the individual being thus scolded, adding to their sense of stigma and taking away from their sense of self and agency.

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.”

Sameera Shamim adds from her own experiences of working with parents of children with disabilities, “It has often been seen that in most progressive and supportive families too, the care providers

or parents are reluctant when it comes to their child or ward with disabilities engaging in relationships or exploring sexuality. The fear that if a person with disabilities gets married and has children then the burden of providing care to the children will also be the responsibility of the care providers often adds to the reluctance. In addition, the parents or care providers often also feel that it may add to the vulnerability of the child as their exposure is limited and thus they may get into abusive or exploitative relationships.”

People with disabilities are also often regarded to be childlike. This leads 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 sexual and reproductive health, including HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immunodeficiency Syndrome). As C. Mahesh says, “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 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 they can be entitled to SRHR?” And Praveen from Voluntary Services Organisation agrees, “It is hard for disabled people particularly – visually impaired, hearing impaired and mentally disabled to have access to information on sexuality.”

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

153 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. Pp. 3-4

of the genitals can also be sexually gratifying and pleasurable, but these are often not regarded as 'real sex'.<sup>153</sup> Sadly, many people with disabilities also buy into this myth. Or worse, believe that sex is not meant for them.

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?"

These service providers would do well to cast their assumptions aside and read the WHO-UNFPA Guidance Note that 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>154</sup>

154 WORLD HEALTH ORGANISATION and UNFPA.2009. Promoting Sexual and Reproductive Health for People with Disabilities.

False assumptions, such as those elaborated in this section, can lead to inhumane practices. 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>155</sup> This 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 non-sexual 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.

155 The International Secretariat of the World Organisation Against Torture (OMCT). 2008. India: Inhuman and Degrading Treatment of Mentally Ill Women Patients in a Public Hospital. Geneva, 20 Retrieved from <http://www.omct.org/violence-against-women/urgent-interventions/india/2008/03/d19201/>

## Sexuality and Disability in the Media

Media today is an all-pervasive part of most people’s lives, accessible at the touch of a button or a swipe on a phone capable of running social media apps or even instant messaging applications such as WhatsApp. Media encompasses film, advertising, TV, print, outdoor and online tools and platforms with a vast potential for mainstream communication. A good question, as Janet Price asks is, “Where are the representations of disabled people? And particularly disabled people as sexual, in relationships, dressed smartly and looking desirable during their working life, having children, managing divorce for issues *not* to do with disability? Currently they only occupy niche sites.”

Sameera Shamim feels that today, “Globally this trend is changing, though slowly, as now we have dolls which have been introduced as disabled or there are characters in cinema who are portrayed in a positive light as independent characters and not negative dependent characters.”<sup>156</sup> Glimpses of this may be seen in media and popular entertainment. The TV serial ‘Mom’ for example, plays out a relationship between Bonnie, one of the main women characters, and Adam, a wheelchair user. In India, some attempts have been

156 Sameera Shamim. 2017. Personal communication.

made in Bollywood cinema to create and present characters with disabilities. Though these representations have sparked debate and argument over the handling of these characters, there has been greater visibility and discussion of concepts of ability and disability as a result of these ventures.

Nidhi Goyal, who incidentally also performs stand-up comedy, made her debut performance as India's first visually impaired comedian in February 2017.<sup>157</sup> Like Sameera, Nidhi also observes that today media does cover sexuality and disability. She cites the example of the film *Margarita with a Straw* (2014), a sensitive portrayal of a young woman with cerebral palsy exploring her sexuality. "As a film, *Margarita With a Straw* was significant in opening up/ pushing conversations on sexuality and disability. It directly challenged the hierarchy of needs that is assumed for people with disabilities which leads to focus on one aspect at the expense of another, unlike in the case of persons without disabilities."

157 MITTAL, A. (2017. February 15). *Bad Girls with Aditi Mittal, Episode 1, NidhiGoyal*. [Video file.] Retrieved from <https://www.youtube.com/watch?v=9QBF23jouT4>

Shweta Ghosh's film, *Accsex*, is another effort that looks at concepts of body, at the 'ideal body' and explores questions of relationships and sexuality through the eyes of protagonists who are women with disabilities.<sup>158</sup>

158 PSBT India. (2015. May 18). *Accsex*. [Video file.] Retrieved from <https://www.youtube.com/watch?v=nkh7gS9e7s8>

In general though, ignoring the existence of persons with disabilities, across fields of focus that may or may not be directly connected to sexuality, continues. In September 2016, when the Rio Paralympics were held, despite India sending a big contingent of 19 athletes, including 3 women, to the games, national television broadcasters did not initially plan to cover the games, unlike the response to the Olympics held just the previous month.<sup>159</sup> It took the voices and efforts of NGOs and the athletes themselves before some minimal regular coverage was undertaken by some TV channels. Para athlete Pradeep Raj, founder of the Para Sports Foundation said, "To discuss this injustice and discrimination against Indian athletes with disabilities, the first Indian-origin person selected to serve as Chaplain for the Olympic and Paralympic Games, Rev. Zenji Nio has skipped the opening ceremonies in Rio and flew in from the

159 DNA. (2016. September 6). Unlike Olympics, no TV coverage for Rio Paralympics in India. Retrieved from <http://www.dnaindia.com/sport/report-unlike-olympics-no-tv-coverage-for-rio-paralympics-in-india-2252594>

Olympic Village to discuss this issue in landmark press conferences being organized in both Kolkata and New Delhi by the Civilian Welfare Foundation.”<sup>160</sup> The Paralympics are an international event of a high profile. In India, media would not have included even this event in their broadcast plans, had they not been pushed to do so by the efforts, activism and advocacy of a small section of people, and by the amplification of these voices on social media. This illustration relates to the visibility of disability in media focusing on sports, a subject likely to garner great enthusiasm for medals and accolades amongst audiences. Sexuality, a far more complex issue, is less likely to be visible in the frame of disability focused and disability sensitive media content.

In an online current affairs magazine, *The Diplomat*, an article dated 22<sup>nd</sup> December 2016 focuses on an even more telling media response, or lack of response, to a crucial and historic piece of news, the passage of the Rights of Persons with Disabilities Bill 2016. The article rightly asks:

Shouldn't the media have focused their attention on the bill, even for just a day? The print media was only slightly better as most of them covered the passage just as a news report. None of them analysed the bill deeply. The pros and cons of the 58 amendments in the bill were left undiscussed. When the bill was passed in the Rajya Sabha, not a single newspaper put this as its front page headline. Only the online media showed some hope, with some good analytical pieces on the bill. Media houses may argue that it is their prerogative to decide what to discuss at length and what to focus on. This is true, but their focus shows that disability rights are not on their 'priority list' and never were.

In this ratings-driven world, media organisations chose to cover topics that will grab more eyeballs. They know that a very large percentage of the differently abled population don't have access to their channels or their newspapers and hence that population doesn't matter much to media executives. This low coverage of disability-related issues is a chronic problem, not

160 ANI. (2016. September 8). Lack of media coverage for Rio Paralympics in India draws flak. *Deccan Chronicle*. Retrieved from <http://www.deccanchronicle.com/sports/in-other-news/080916/lack-of-media-coverage-for-rio-paralympics-in-india-draws-flak.html>



161 JHA, M. (2016. December 22). Why Did India's Media Ignore the Disability Bill? *The Diplomat*. Retrieved from <http://thediplomat.com/2016/12/why-did-indias-media-ignore-the-disability-bill/>

just a one-off case.<sup>161</sup>

This commentary comes at a time of great change in the landscape of disability legislation in India. It comes from a media house and calls out the entrenched injustice and discrimination towards disability as a theme.

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 quarter of a century. 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, there have been TV debates and news coverage regarding sexuality education in schools. The 2009 Delhi High Court ruling on reading down Section 377 of the Indian Penal Code that criminalised same-sex sexual behaviour and the Supreme Court verdict of 2013 that set aside the High Court's ruling and upheld Section 377 led to many conversations and intense debates across the country. Events such as these, and the gang rape and murder of a young woman, Jyoti Singh, in December 2012 in Delhi, have 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 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.

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.

The website Sexuality and Disability was launched by Point of View with the support of CREA in April 2012.<sup>162</sup> It offers information, tips, personal narratives and more on sexuality and disability. Following the launch of the website, Disability News and Information Service (DNIS) interviewed Geetanjali Misra (Founder, CREA) to explore the gaps that led to the decision to create a website focusing on disability and sexuality. In this 2012 interview, Geetanjali has spoken of how the sexuality conversation has left out women with disabilities as the disability becomes the prime marker of identity. She says:

Sexuality is all pervasive and affects everyone. Whether it is about growing up, partnerships and relationships, health, or fulfilling lives, sexuality has links to all. In a society like ours, sexuality itself is a taboo subject. And, talking about disability and sexuality, that too focussing on women, is a huge challenge. There is a great amount of wrong assumptions about sexuality of women with disabilities – they are considered to be asexual or that it is a perversion to talk about their sexuality. These factors lead to the silencing of such subjects. Women need the agency to speak about their lives, their bodies, their sexualities themselves, so that they can claim their rights and live lives as they want to.<sup>163</sup>

Actual sexual practices, experiences, adaptive techniques, capabilities rather than ‘disabilities’, need attention. Women with disabilities, LGBTI people with disabilities, as well as young people with disabilities face discrimination at multiple, intersecting levels.

162 POINT OF VIEW. Home – Sexuality and Disability. Retrieved from <http://www.sexualityanddisability.org/>

163 SHARMA, D. (2012. May 15). Sexual and reproductive rights of women with disabilities is a marginal issue on the agenda of disability rights organisations, Geetanjali Misra. *DNIS*. Retrieved from [http://www.dnis.org/interview.php?issue\\_id=5&volume\\_id=9&interview\\_id=193](http://www.dnis.org/interview.php?issue_id=5&volume_id=9&interview_id=193)

For example, gender or sexually non-conforming people with disabilities are subjected to multiple discriminations on the basis of disability, sexual preference, and aspects of gender. As Nidhi Goyal, who co-researched and co-authored the Sexuality and Disability website, observes, given the lack of accessible information, to find people standing at this intersection where they are dealing with issues of sexual identity and of disability is a huge challenge. She speaks of her experience while researching for the website, when apart from the mental health segment, it was difficult to find anyone else identifying with a non-heterosexual orientation. “If you’re queer and disabled you don’t know what is happening – or what it’s all about. Even if you know about, identify, understand and accept your identity, how do you engage with others?” The complexity intensifies due to challenges of communication, and dependence on care providers and interpreters, with “limitations of access to information, spaces and people”.

## Body Image and Self Worth

One of the foremost concerns or anxieties that people had about sexuality on the TARSHI helpline that ran from 1996 to 2009 used to be that of body image concerns especially about the 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 people with disabilities, especially women and girls, as there is a higher premium on beauty for girls in relation to boys.

In 21<sup>st</sup> 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. 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, feelings of incompleteness and feeling unworthy of sex, love, companionship, marriage etc. Low self-worth and dependence on others could also cause people with disabilities to not seek healthcare.

Renu Addlakha notes:

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 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>164</sup>

164 ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity.

It is no wonder then that they are so unprepared for adult relationships of any kind, let alone those that are sexual.

Curiosity about issues of sexuality and relationships by a person with disabilities is often considered inappropriate. Persons with disabilities do not have the same opportunities to share thoughts and experiences around relationships and sexuality. This lack of interaction even with peers, affects the development of a positive body image, self-expression and self-esteem.

“Most times, there is no concept of choice or consent amongst the disabled participants and even rare in disabled women”, says

165 POINT OF VIEW. Workshops  
– Sexuality and Disability.  
Retrieved from <http://workshop.sexualityanddisability.org/>

Nidhi Goyal, speaking of her experiences at sexuality and disability trainings that she conducts for Point of View<sup>165</sup>. When asking questions such as ‘What do you understand by relationships?’ or ‘Who could be your potential partner?’, she finds that the maximum focus in the responses is on whether the partner is disabled or not, and if disabled then which disability. The idea is not of liking, or love, or choice, or anything else; it is just about the disability and managing and support. The effort is to bring back the focus on the individual or the person who would be the partner and not the disability, but it is challenging because most participants internalize the reductionist attitude of society.

The other problem Nidhi points out is the normalising of discrimination and violence. For example, the attitude that a woman with a disability is not going to get married or not going to be a ‘good mother’ is accepted by women and girls with disabilities unquestioningly. In workshops with young girls with disabilities, Nidhi has asked participants whether they have faced any kind of abuse in public spaces, and most often the answer is no. When she breaks it down to ask questions such as, “has someone tried to touch you inappropriately when you cross the street?”, or, “how many relatives have sat and said you are good for nothing?” participants respond differently, saying – yes, that happens all the time and that they are treated as ‘damaged goods’. When abuse and discrimination is so pervasive in the environment, people with disabilities normalise it, internalise it and in some cases perpetuate it, says Nidhi.

In perpetuating, they become discriminators. Conversations in workshops have highlighted that participants have very little regard or patience with another disability and consider the other disability to be very problematic, at the same time there have been conversations where non-disabled counterparts are clearly valued above disabled counterparts. The latter attitude is seen mostly in men with disabilities, that they feel that non-disabled women as partners are far better than disabled women as partners. In one workshop adolescent men with disabilities sat with girls with disabilities

their age and mentioned that if they had a wife it was okay to beat her if the wife was disabled and not okay to beat her if she was not disabled. Women with disabilities are more flexible in their partner choices because they feel that only a disabled man would “accept” them. Both these attitudes are a byproduct of gender discrimination and ableist socialisation. “The key to counter this is first to visibilise the existence of this normalization and internalization and then challenge it in steps,” says Nidhi.

“It basically starts from the understanding of self, self-worth and self identity”, says Nidhi. “The concept of self is so unstable and an own voice is so alien, for girls and women with disabilities in particular, that when we start the workshops with a simple ice-breaker of ‘tell us your dream’ they are stunned into silence – perhaps because they internalize external voices so strongly that they find it hard to find an internal voice, perhaps because this is the first space where they count as individuals and not just as someone disabled. To recognise yourself as a being first with hopes, and dreams, and choices, and a voice is the beginning of a long process of empowerment and growth.”

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.

Based on experiences shared with her, Sameera Shamim says, “In today’s day and age of technology, there are people with disabilities who are accessing portals like ‘Tinder’ to engage with others and explore possibilities of relationships. However, the experiences of persons with disabilities reflect that the conversations or interactions are great till the other person discovers (the fact of) their disability. However, there have also been instances, though few, where it has led to friendships.”

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. Shivjeet is quadriplegic. In a 2015 news article online, he has been quoted as saying, “Sex is between our ears,” and “I still feel attracted to women just as I did before. Sex is equally about your partner, and his or her happiness”.<sup>166</sup> It is a positive sign of progress that increasingly media attention is focusing upon the voices, experiences and observations of people with disabilities who speak of sexuality.

166 SINGH, I. (2015. March 15). Willing and able: More and more differently-abled are discussing sex. *Hindustan Times*. Retrieved from <http://www.hindustantimes.com/sex-and-relationships/willing-and-able-more-and-more-differently-abled-are-discussing-sex/story-uYgTeGCLEBSLpEiQnMLHCM.html>

The challenges faced by those who develop a disability later in life can be different. Having lived without a disability for a part of their lives, those who develop disabilities due to accidents, surgery or illness 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, with sexual arousal and with their partner, and their perceptions of self, may change drastically. 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.

## Relationships

In the 2012 global report on inclusive communities by Inclusion International,<sup>167</sup> researchers have presented the voices of self-advocates with intellectual disability and their families, speaking of themselves in relationships with their families, friends and loved ones. Some voices from around the world include:

“I want him to be able to take care of himself and to live in the community like any other person, without discrimination. I want my son to be included.”

“My family did not want me to live in a home away from them, but we decided to try independent living. If all went well perfect, but if not, then nothing would happen, I could come back to their home. I know that always I have my family with me. The problem comes when you have no one and you are helpless”

“One of the positive features of Indian society is that persons with disabilities generally live with their families in majority of cases. However there are times when natural parents are no more and when no support is available by the extended family, they face a severe problem. This problem is very acute among nuclear families and in urban areas.”

“You only know that you are respected when you live in the community.”

“There are discotheques where they won’t allow people with Down Syndrome. I saw it on television.”

Three themes have been articulated as central to the voices and vision of participants and respondents in the above-mentioned study – choice, support and inclusion. Choice and to be able to decide for oneself from those choices; with support as needed for such decision

167 INCLUSION INTERNATIONAL. 2012. *Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and Be Included in the Community*. ISBN 978-0-9917430-0-1. ©2012 by Inclusion International. Retrieved from <http://inclusion-international.org/wp-content/uploads/2013/07/Global-Report-Living-Colour-dr2-2.pdf>



making, disability related services and support being available as may be required on a day-to-day basis; and inclusion as a feature of community life, are crucial issues. Article 19 of the CRPD focuses on living independently and being included in the community. The right to choose, make decisions with support as may be required, to engage with people and create, build or maintain relationships with family, friends and others, is at the core of inclusion.

An excellent articulation of this in the Inclusion International report explains:

To effectively implement Article 19 we need to stop telling families that people with intellectual disabilities are going to live independently. To many families that sounds as if people will live alone and Article 19 does not call for people living alone nor does it call for people to live without needed supports. Article 19 does not define independence as people living alone but rather is about choices and control of one's life. Living alone is not the goal, though some people may prefer to live that way. However even people who want to live alone do not want to be lonely. Humans are dependent and interdependent on other humans. Interdependence is a good thing; it is desirable. Multiple studies show that people with disabilities are all too often lonely. Studies also show that when you live with a lot of people who are not your family you are more likely to be lonely than when you live with a few people. Study after study also show that we can help people with all levels of disability plan and take control of decisions large and small impacting their lives. We sometimes call this "person centered planning and supports." The goal of Article 19 and the CRPD is interdependence, self-governance and self-determination, not independence from other human beings.

Unfortunately, people with disabilities in India 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 over-riding 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 a dominant 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 are hurdles 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.

168 NATIONAL RESTAURANT ASSOCIATION OF INDIA. (NRAI). 2015. Nipun's mission to make restaurants 'a pleasure' for India's disabled. Retrieved from <http://nrai.org/making-restaurant-visits-a-pleasure-for-indias-disabled/>

169 DASH, N. (2015, March 7). Disabled activist denied entry to Delhi restaurant, inquiry ordered. *India Today*. Retrieved from <http://indiatoday.intoday.in/story/disabled-activist-denied-entry-to-delhi-restaurant/1/422635.html>

In 2015, Nipun Malhotra a disability activist and self-advocate challenged exclusion by working to have an online restaurant listing company, zomato.com, list restaurants that are wheelchair and disabled friendly.<sup>168</sup> Nipun himself was in the news for having been denied entry into a Delhi restaurant with his friends. The group was told that as a policy the restaurant does not allow entry to 'disabled people'.<sup>169</sup> He says, "It was a struggle to find disabled-friendly restaurants in Delhi and other Indian cities before Zomato agreed to my request. Not many places advertised themselves as disabled friendly and that was disheartening. Most disabled people in India do not visit restaurants very often and that severely restricts their social life." While such efforts go a long way in challenging the established exclusionary policies and mindsets in society, they are few and fragmented still. Coordinated efforts across domains are required to build effective support and change the environment and infrastructure to be enabling as opposed to disabling. Such initiatives promote well-being and self-confidence, making it easier for people to meet, socialize, foster relationships and explore and express their sexuality. The availability of social, recreational and physical spaces, of opportunities, of access, the question of self-esteem, self-image and self-confidence, as well as privacy issues, all influence inclusion. Therefore too, they influence the possibility and potential to explore any independent relationships, in theory and actuality.

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

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.

According to Shalini Khanna, “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.”

## 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 WOHTRAC 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>170</sup> Similarly non-disabled women from lower socio-economic strata are often married to men with disabilities

170 KHANNA, R., et al. 2004. Consultative Meet on Gender and Disability.

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. If the issue relates to a woman with an intellectual disability, it is inconceivable for most people that she be considered for marriage. The Bapu Trust works with individuals and family care providers dealing with intellectual and developmental disability. Bhargavi Davar speaks of a case where "the family wanted to get one such individual married. Initially, senior staff at Bapu Trust were hostile to this idea. They did not grasp that IQ is not the same as EQ. Low IQ does not equal low EQ. So the sexual needs of a person with intellectual disability are not addressed, nor their emotional or relationship needs. Ultimately the person being referred to in this case did get married." Speaking of such cases, she points to a big gap in the capacity of teams to address sexuality and gender issues in the field with service users and their families.

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 untrue and overriding fear that people (especially women) with disabilities will also always produce children with disabilities.

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.

As pointed out in the paper, *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*,

In the case of people with disabilities, particularly persons with psychosocial disability, marriage has been seen as a range of things that often have very little to do with rights such as right to intimacy, companionship, and sexuality. Some of the primary motives include marriage as cure of illness, as source of unpaid long-term care, assurance for old age, and so on. Thus, while on the one hand, the marriageability level of people with disabilities is seen as low, marriage, particularly for disabled men with poorer non-disabled women, or women who are not seen as highly desirable in the marriage “market” such as divorced, widowed women, or even women with lesser degree or more hidden nature of disability is seen as a solution by parents and family members for long-term care of the person. Non-disclosure of mental illness prior to marriage is another issue that is partly linked with looking at marriage as an opportunity to shift burden, not just of care but also of the shame associated with an unmarried daughter living with mental illness.<sup>171</sup>

Renu Addlakha believes 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>172</sup> 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

171 RANADE, Ketki, and ANJALI—MENTAL HEALTH RIGHTS ORGANISATION. *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*. Kuala Lumpur: Asian-Pacific Resource & Research Centre for Women (ARROW), 2017. Retrieved from <http://arrow.org.my/publication/sexual-rights-women-psychosocial-disabilities-india/>

172 ADDLAKHA, R. 2007. *Gender, Subjectivity and Sexual Identity*.

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 with disabilities than men with disabilities.

Several commercial marriage bureaus in India play a role in connecting persons with disabilities to potential marriage partners. As Nidhi Goyal says, “Unfortunately, all of it is about the disabled marrying the disabled. Inevitably this is the only choice there is. Again, we return to the reductionist approach of society.” Popular Indian matrimonial websites like Shaadi.com<sup>173</sup> and Bharat Matrimony<sup>174</sup> have special sections for people with disabilities on their websites. However, these are not immediately visible upon accessing the sites. In addition, it is quite often obvious that the communication from the marriage bureau is dictated by the saleability of the idea, the market need for the service. This has its positive and its dark side.

173 SHAADI.COM Indian Matrimonials. Retrieved from <http://www.shaadi.com>

174 BHARAT MATRIMONY. Indian Matrimonials. Retrieved from <http://www.bharatmatrimony.com/>

Bureaus bring the matter out into the open, for public discourse, quite directly. They offer a platform for interaction, which is in alignment with the marriage bureau culture in India. They do not explore, initiate or attempt to shift existing attitudes and behaviours. They continue for the most part, to use the word ‘handicapped’. For example, Jeevansaathi.com on their website has a category they call ‘Handicapped Matrimonial’. Their description, up on the website as in January 2017, reads:

A person with a physical disability because of illness or accident is termed as ‘Handicapped’. These people get government assistance to start income generating activities. Even the Handicapped persons, just like healthy persons, want to share their joys and sorrows with someone special. Handicapped Matrimony is a dignified gesture, as people with physical disability wants to tie the nuptial knot and lead a happy life. This platform unites likeminded persons for physically challenged matrimony.<sup>175</sup>

175 JEEVANSATHI. Handicapped matrimonial. Retrieved from <http://www.jeevansathi.com/handicapped-matrimony-matrimonials>

The 'About' section of the website of Handicapped Marriage says:

Special Case (Handicapped, Deaf, Mute, Physically Challenged) Indian Matrimonials Register Now For FREE. We CARE that's why we have special section for handicap matches. Find profiles of Deaf, Mute and other Handicapped Brides and Grooms from around the world. If you are handicapped looking for a handicapped matrimonial or dating match, add you profile (bio-data) for Free and see the result.<sup>176</sup>

176 HANDICAPPED MARRIAGE. Retrieved from <http://www.handicappedmarriage.com/about.php>

The website iMilap.com has used the same lines including "We CARE that's why we have special section for handicap matches."<sup>177</sup> This easy borrowing of language between one site and another does nothing to initiate change in attitude or approach, nor does it build confidence in any way.

177 IMILAAP. Special case search. Retrieved from [www.imilap.com/Indian-Dating-Matrimonial-handicapped.asp](http://www.imilap.com/Indian-Dating-Matrimonial-handicapped.asp)

In this online piece describing the efforts of octogenarian Prabha Panse who in 1989 set up a marriage bureau called Jeevan Saathi Marriage Bureau (no connection with jeevansaathi.com) in her home, her own description of her approach is "This is not a place where you will marry someone who has the same disability as yours. There are deaf people who have married someone without legs or someone suffering from polio." People respond to these efforts and Panse has arranged close to 500 such marriages.<sup>178</sup>

178 SHUKLA, S. (2012. January 15). Perfect Partner. *Indian Express*. Retrieved from <http://indianexpress.com/article/cities/mumbai/perfect-partner/>

All of this only goes to show that there is a great need to create platforms where people with disabilities can have social and romantic interactions, and where sexuality and disability can be discussed. However, the content, the ideas and the vocabulary of these conversations must change. While it is sometimes heartening to note the initiatives that spring from well-intended sources, it is important to discuss some of the attitudes that accompany these initiatives since they tend to perpetuate stigma and isolation. It is also important to challenge the approach taken by commercial ventures that ignore the rights based communication, concepts and advocacy led by activists and self-advocates.



## 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 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. 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, “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>179</sup>

<sup>179</sup> KHANNA, R., et al. 2004. Consultative Meet on Gender and Disability.

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>180</sup>

<sup>180</sup> GHAI, A. 2009. The Women’s Movement Must Do More.

Kuhu Das from the Association of Women with Disabilities (AWWD), 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 non-sexual? 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 non-sexual.

Anita Ghai quotes a woman with cerebral palsy called Disha who says, “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>181</sup>

181 GHAI, A. 2003. (Dis) Embodied Form.

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 are non-sexual, 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.

The authors of a report of a 2007 multi-state (Orissa, West Bengal, Chhattisgarh, Andhra Pradesh) study of women with disabilities in India note:

The disadvantage of gender and disability aggravate the

existing gender gap among persons with disability in various aspects of entitlements and functioning. This ‘not so obvious’ assertion is then examined with reference to the secondary data available from the four states. In doing so the first problem one faces concerns the nature of the data. Much of the public domain data is gender blind and even more so disability blind. Nevertheless, the available data does show an accentuated gender divide in the disabled population whether we look at literacy, schooling, access to work or employment.<sup>182</sup>

182 UNDP – Government of India – SMRC Study. 2007. *A Multi State Socio Economic Study of Women With Disabilities in India. Report.* Bhubaneswar. Retrieved from [http://www.undp.org/content/dam/india/docs/a\\_multi\\_state\\_socio\\_economic\\_study\\_of\\_\\_\\_with\\_disabilities\\_in\\_india.pdf](http://www.undp.org/content/dam/india/docs/a_multi_state_socio_economic_study_of___with_disabilities_in_india.pdf)

Commenting on the findings of this report, Dr. Anubha Rajesh observes, “Women with disability face the twin challenge of gender bias and disability. This poses access barriers to their rightful entitlements such as aids and assistive devices, training, pension, or education. While the study emphasizes the need to be economically independent, be engaged in jobs that may be low paid but have a steady income, it also points out the issues of safety that women with disability sometimes face with mobility and travel to and from the workplace. Additionally, issues of violence and sexual harassment at the workplace are also flagged by the study. To conclude, the study highlights the need for budgetary analysis of the disability sector.”

## Sexuality Education

In India, sexuality education is yet to be included in the school curriculum. It is ironic that over 60 years have passed since India launched its Family Planning Programme (1952), over 45 years since abortion was legalised in the country (1971), over 30 years since the first HIV infection was detected in the country (1985) and over 20 years after the International Conference on Population and Development (ICPD 1994), there is still silence and confusion about the importance of providing sexuality education to young people. Sexuality education continues to be one of the most debated issues in the country. 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 'how to have 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, possible consequences of various actions/behaviours, and also how to protect themselves from unwanted and harmful consequences of these actions/behaviours, in addition to addressing feelings and values and developing skills of communication, assertiveness and negotiation around relationships.

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. The FST study with young people with disabilities found that, "Only 27% of respondent youth were ever exposed to educational sessions pertaining to sexuality and sexual health. However, most of them (77%) felt that it is very important to have such sessions in their institutes/organisations."<sup>183</sup>

Where information on sexuality is provided, it is largely limited to information on menstrual management and hygiene for girls and about prevention of abuse. Sameera Shamim flags another issue: this exercise is also often conducted without considering the appropriate communication methodology, thus ignoring that different types of impairments impose different challenges to communication and understanding. Information about safer sex, contraception and other sexual and reproductive health concerns is not given as it is

183 FOUNDATION FOR SOCIAL TRANSFORMATION. 2016. *Understanding Sexual Health & Rights of Youth with Disabilities in Assam - A Study.*

often thought of as irrelevant for people with disabilities.

The CREA report has presented some of the responses of interviewees thus:

Some other points that were said about providing such information to people with disabilities are “Because sometimes our girls have a cognitive function problem as well. So it becomes very difficult to save them and protect them”. Another respondent said, “they don’t know the social way of conducting themselves”. Yet another response was that if this information is not provided, “they can’t distinguish between good and bad touch”. One of the respondents said that people (with disabilities) enter relationships without adequate information and added, “Deaf people are at heavy risk of HIV”. In the context of organisations working with younger disabled men and women, a respondent mentioned that there is a lot of exploitation even at homes and there are no laws to protect younger people, therefore “all we can do is ensure that the children know about it.” These respondents also mentioned that giving such information in school settings is very challenging and that parents of disabled children fear the natural process of sexuality, as they aren’t sure how to communicate with their children about such needs.<sup>184</sup>

<sup>184</sup> CREA, ANJALI MENTAL HEALTH RIGHTS ORGANISATION, POINT OF VIEW, EQUALS CENTRE FOR PROMOTION OF SOCIAL JUSTICE and SRUTI DISABILITY RIGHTS CENTRE *Needs Assessment Report- Addressing Disability and Sexuality Rights, Closing the Gap – Building Institutional Capacity to Address Sexuality and Disability. (2016) (Unpublished Draft)*

The website [sexualityanddisability.org](http://sexualityanddisability.org) attempts to change mindsets in different ways. For example, there is a section on the site titled ‘Attention Families’ where the communication is directed at changing the parental perspective:

Don’t assume your daughter will not need information regarding sex and reproduction.

Don’t assume your daughter is not interested in sex, just because she has never asked you about it.

Equip yourself with enough information so that you can answer her questions.

If you are uncomfortable discussing these issues, practice

beforehand with a friend or your partner. If you are embarrassed about sex, your daughter will also treat it as a shameful subject.

Teaching the difference between good, bad and necessary touch can be a simple but useful way of explaining abuse.<sup>185</sup>

Activists in the field believe that sexuality education is important for people with disabilities. Pramada Menon says that whenever the suggestion about introducing sexuality education for people with disabilities is broached, she finds that people with disabilities not only agree with the idea but also report feeling validated that their experiences and needs are being acknowledged. Deepa Nair feels that “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”.

There are 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 or old the child might be.”

In TARSHI’s 2010 working paper, Shampa Sengupta recounted an experience saying:

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 caregivers would 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.

Things have progressed since then and Shampa continues to

185 POINT OF VIEW. Attention families – Sexuality and Disability . Retrieved from <http://www.sexualityanddisability.org/having-sex/mythbusting/attention-families/>

conduct and facilitate workshops on sexuality and disability in schools and with parents, teachers and care providers. She spoke of one such workshop held at a Kolkata school where the concerns prior to conducting a workshop revolve around participants ability to confront issues that they are conditioned to ignore, whether they can face the sexual agency of their children and is it possible to look at the intersections of sexuality and disability.

According to Sameera Shamim, “Often institutions and the people heading these institutions also become critical when it comes to sexuality education for persons with disabilities. In my own experience of working with Indian Institute of Cerebral Palsy (IICP), where the head Dr. Reena Sen considered this very important, such sessions were held to provide information, enhance knowledge and also be used as a space to share and discuss feelings and experiences. Sessions held with groups of girls and boys with cerebral palsy at the institute highlighted their need and curiosity to know more, and the lack of information which is accessible and easily understood. The sessions revealed that those who used the Internet regularly were afraid that if they are caught accessing these sites at home they will receive a scolding. The other scenario was where they did find information, it either left them confused or they wanted more information and had no one to ask.”

Shashi Paul from Deepalaya was quoted in the 2010 paper as saying:

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 believes, “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 2007 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.”<sup>186</sup>

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. For the 2010 paper, Nithya Balaji reported that 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 added, “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.”

During the course of the FST study the researchers asked teachers about their comfort with discussing sexuality issues with young people. The FST report says that, “Most of the teachers (23) said they felt extremely or fairly uncomfortable while discussing such issues with YwDs” and that, “While most teachers interviewed agree that sex and sexuality issues must be part of the regular curriculum in

186 MOLL, K. 2007. *Too Few to Worry About? Or too Many to Ignore - The Exclusion of People with Disabilities from HIV Programmes in India*. Retrieved from <http://www.hivpolicy.org/Library/HPP001232.pdf>



187 FOUNDATION FOR SOCIAL TRANSFORMATION. 2016. *Understanding Sexual Health & Rights of Youth with Disabilities in Assam - A Study.*

their institution, most are not comfortable discussing it with the youth. In fact, 3.7% of teachers did not even know how women get pregnant.”<sup>187</sup> This last fact emerging from this study is in itself indicative of the glaring need to bridge knowledge gaps amongst this group of care providers to children with disabilities.

Nidhi Goyal points out that in India, till date, providing sexuality education is challenging in all schools, forget about only special schools, and even if it is provided, it is not delivered in an accessible formats for students with disabilities. “There is a huge gap in knowing about bodies, sexuality etc. across age groups of people with disabilities. So for our workshops, we not only reach out to special schools but also disability rights organisations. This is the easiest way to access persons with disabilities, in an environment that is accessible for them, and the environment they trust – particularly for girls / women with disabilities. But many disability rights organisations act as gatekeepers to information as well. There is a strict policing on the topics that we can cover – so sometimes they want us to cover menstruation and hygiene but not reproductive process, in others they are keen on HIV information but not on body literacy. It needs a lot of advocacy and sensitization to provide comprehensive sexuality education. There are also intangible gains of sexuality education, and it is very difficult to make organisations understand these.”

Despite these barriers identified by resource persons working in the field, a positive note has found expression as well. Shampa Sengupta feels that sexuality issues are now more commonly discussed in the disability sector and observes, “In almost all special schools, sexuality issues are discussed whereas in mainstream school, these remain untouched”. However, it is important to put this in the context of some of the experiences shared by others. Since the late 1990s when TARSHI first began conducting sessions for ‘special’ schools, the call invariably came after there had been an incident involving students, or even teachers, that the school found difficult to handle. For example, of students masturbating or flashing, or of abuse of a student by a care provider or helper and other such issues. So, while

it may be that in 'special' schools sexuality is spoken of more often, it is almost always in the context of a problem to be solved and not as an inherent right to information and wellbeing of students with disabilities. One may assume the need to explore the quality of conversations, knowledge content and attitudes of those involved in this discourse, to whatever degree, across levels of expertise or lived experiences as in the case of parents and family care providers.

## 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.

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.

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. 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. Also, the lack of privacy for people with disabilities becomes a barrier in every way.

Also as Lakshmi Ravikanth of The Banyan says, “Disability for persons with mental illness and mental retardation are double edged; as functionality increases, personal expressions of desire are implicitly or explicitly communicated, and the latter is very often construed as an aberration, the denial or ignoring of which entails a tendency to ‘relapse’, which affirms the illness perspective. Somehow once labelled ill... sexuality seems to be governed by the ‘illness and wellness paradigm’.”

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 apart from the website [sexualityanddisability.org](http://sexualityanddisability.org) that we mentioned earlier. The only other 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>188</sup>

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, their 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>189</sup>

189 Ibid

In a 2016 article online, Dr H S Chhabra, Chief of Spine Service & Medical Director, Indian Spinal Injuries Centre says:

One aspect of spinal injury that does not receive much attention is its implication on the sexual health of the affected person, especially in Asian countries and India. Since discussing sexual health has always been a taboo in a large part of the Indian society, talking about this subject is often not encouraged, and patients continue to suffer in silence. Owing to the lack of education, knowledge and awareness, people tend to believe such patients to be bereft of sexual desire and need. However, the truth is, sexual activity is as important for a spinal injured as for any normal person. Sexual expression is a fundamental part of being human and an important component of one's identity and this is as important for a spinal injured.<sup>190</sup>

What Dr. Chhabra says of spinal injury, is true of most conditions that cause or are due to impairments. The words 'spinal injury' and 'spinal injured' may be substituted with any other term descriptive of impairment and disability, and the message remains the same. Thus the invisibility of sexuality persists even though some individuals

190 CHHABRA, Dr. H.S. 2016. Rediscovering sexual health after spinal cord injury is possible. *eHEALTH*. Retrieved from <http://ehealth.eletsonline.com/2016/06/rediscovering-sexual-health-after-spinal-cord-injury-is-possible/>

and organisations have sustained their efforts to give the subject space in the disability discourse. The need to expand such efforts remains.

Another crucial reason why it is important to bring these matters out into open forums for discussion is because of the way they connect to other areas important to human rights, development, society and sexual and gender stereotypes. In the same article quoted earlier, Dr. Chhabra goes on to say:

In case of an SCI, [Spinal Cord Injury] it is often easier for women to become a sexual partner than for a man not only due to anatomical reasons but also vis-à-vis the level of activity. Given the disassociation of sexual desire from women in conservative societies, such as India, 80 per cent of the time women in India are passive sexual partners, in that they do not initiate the act. Rediscovering sexual health therefore is easier for women than in men, and their main focus has to be on rediscovering sexual desire and ability to have intercourse.

Dr. Chhabra also says:

Sexual relationship between husband and wife are mainly thought to be for begetting children. Discussion about sex is considered taboo. Sexual problems are not only common, but also are mainly related to ignorance, misconceptions and negative attitudes towards sex in general and cultural taboos in particular. Other socio-cultural factors affecting sexuality include the sexual attitudes and values of parents and others that sex is 'dirty' and the double standards of behaviour for men and women. Women are in a disadvantageous position compared with men.

There is much to think about in this communication as it appears to challenge the norm, points out how the stereotypical expectation from a woman as a passive sexual partner could make sexual acts and practice 'easier' for her, and also talks about the double standards around sexual behaviour.

The experience of sex work and sex workers is an area that offers a different frame of understanding, and has been explored by organisations such as SANGRAM, a rights based organisation focusing on people in sex work, and Point of View. These two organisations along with Veshya Anyay Mukti Parishad (VAMP), a sex workers collective in Maharashtra, India, collaborated to produce a series of short film clips interviewing women with disabilities who are sex workers.<sup>191</sup> Like many other sex workers these women considered sex work as a livelihood option. They found it to be a viable and independent means of making a living, even though at times their disability led to their being initially rejected by a potential client (in the case of visible disability) or being underpaid (in the case of hearing impairment). However, as one of them points out, through sex work she got “both money and sex”.

191 POINT OF VIEW and SANGRAM. 2014. *Lives of sex workers living with disabilities from VAMP*. Retrieved from <http://www.tarshi.net/inplainspeak/videos-lives-of-sex-workers-living-with-disabilities-from-vamp/>

In an online article, Rituparna Borah addresses another aspect of sexual practice, in terms of the barriers and restrictions to intimacy imposed upon women with mental health issues. She writes:

Women with mental health issues are at times not regarded as sexually fit or desirable. In mental health institutions, women are kept as prisoners without thinking of them as sexual beings, with their hair chopped off, made to wear shapeless clothes, and there is no question of talking about desire with them. Intimacy is an important part of sexuality. Sometimes a simple touch can satiate your skin’s hunger. A hug can take the pain away. But how much importance is given to intimacy when it comes to mental health issues?<sup>192</sup>

192 BORAH, R. 2017. It’s time to take back our minds! *In Plainspeak*. TARSHI. Retrieved from: <http://www.tarshi.net/inplainspeak/its-time-to-take-back-our-minds/>

Janet Price points also to the effect of psychotropic drugs on one’s sexual impulses and the limitations of how non-heteronormative sexuality is perceived. Other self-advocates and survivors of the psychiatric system are also more vocally sharing aspects of treatment undergone by them that impact sexuality. In some of the social media conversations<sup>193</sup> and micro-campaigns, including Tweetathons (one of which was also organised by TARSHI), several organisations and activists have spoken about the inter-connections between mental

193 MAPLE JAR. Retrieved from <https://twitter.com/JarMaple/status/862554732350521344>

health, treatments and sexuality.

The paper *Sexual Rights of Women with Psychosocial Disabilities: Insights from India* brings attention upon core issues of psychiatric classifications and diagnosis:

Another set of diagnostic categories in psychiatric assessment that are of particular interest in the context of this paper are sexual dysfunction and disorders of sexual preference. Here, we refer to the International Classification of Diseases 10 ICD-10 (WHO 1992) in discussing these two broad diagnostic categories—F52 and F65. F52 in the ICD-10 is titled, “Sexual Dysfunction not caused by organic disorder or disease” and “covers the various ways in which an individual is unable to participate in a sexual relationship as he or she would wish” (ICD-10, 149). This section is further divided into several sub-sections such as F52.0 Lack or loss of sexual desire, F52.1 Sexual aversion and lack of sexual enjoyment, and so on. It is important to note that there are several underlying assumptions to this section on sexual dysfunction. These include the belief that all sex is heterosexual, all sex is penovaginal penetrative in nature, that there is such a thing as the right amount of sex and right amount of pleasure in sex for everyone.<sup>194</sup>

194 RANADE, Ketki, and ANJALI—MENTAL HEALTH RIGHTS ORGANISATION. *Sexual Rights of Women with Psychosocial Disabilities: Insights from India*. Kuala Lumpur: Asian-Pacific Resource & Research Centre for Women (ARROW), 2017. Retrieved from <http://arrow.org.my/publication/sexual-rights-women-psychosocial-disabilities-india/>

Sexual practice when looked at within the frame of disability rights is a wide ranging subject, that includes attitudes and behaviours of all sections of society that impact the sexuality, rights and sexual expression of persons with disabilities. Sexual practice must be seen in the context of individuals and institutions, social structures and access to opportunity and resources, as they influence the experience of disability.

## Abuse

People with disabilities are vulnerable and subjected to abuse including harassment, violence and sexual abuse.

In a 2016 blog on Café Dissensus, Avinash Shahi, a doctoral candidate pursuing a PhD on ‘Intimacy, Law and Disability: Living with Labeled Identity’, writes of having participated in a workshop organized by the New Delhi-based Centre for Women’s Development Studies (CWDS) in collaboration with the All India Confederation of the Blind (AICB) on the theme ‘Creating bridges between visually challenged women and the Women’s Movement’. He says, “A number of adult blind girls shared their personal experiences of how people in general remained mere spectators in broad daylight while they were subjected to harassment and molestation in the public places”, and, “The workshop attendees from other women organisations were shocked to hear the personal accounts of the blind women. Many among them acknowledged the existing gap between the women’s movement in India and the indifference towards understanding the nuances of disabled women’s daily ordeal.”<sup>195</sup>

It is not only in public places that abuse occurs. 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:

- Limited mobility may result in an inability to escape sexual advances.
- 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

195 SHAHI, A. (2016. August 14). India’s Antipathy: The lonesome fight of women with disabilities for dignity. *Café Dissensus*. Retrieved from <https://cafedissensus.com/2016/08/14/indias-antipathy-the-lonesome-fight-of-women-with-disabilities-for-dignity/>



access to the child with disabilities.

- 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, CY Gopinath and Shilpa Patil conducted 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. Their report *Exploring the Sexual Vulnerability of Urban Deaf Indians* (2000) revealed 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>196</sup>

196 GOPINATH, C. and PATIL, S. 2000. *Exploring the Sexual Vulnerability of Urban Deaf Indians*. Mumbai.

197 UN ENABLE. Factsheet on Persons with Disabilities. Retrieved from <http://www.un.org/disabilities/documents/toolaction/pwdfs.pdf>

A small 2004 survey in Odisha, 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 6% of women with disabilities had been forcibly sterilised.<sup>197</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 passivity and being

seen as non-sexual, 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>198</sup>

Janet Price flags the importance of being aware of the intersection of gender and disability in this discussion, pointing out that men with disabilities “may be feminized, treated as gay and experience violence as a consequence”. Women with disabilities across different socio-cultural contexts will have varying experiences depending on the environment and attitudes around them. Some women living in an intensely patriarchal social environment are at high risk of violence and abuse due to gender and not disability. Nidhi Goyal presents her experience of this particularly with workshops conducted in Uttar Pradesh:

In general, women and girls in the region of Uttar Pradesh are encouraged to stay quiet, and their voices are suppressed. As a result, it took participants a full day even to speak to us. They had rarely been part of a discussion in which they were invited to share their own opinions. When they did open up, they reported that they did not want to get married. This was not primarily because they feared rejection based on their disability, but because they had witnessed severe domestic violence. (“Men are bad because they burn us for dowry,” one participant said.) They affirmed that after marriage, a man is able not only

198 MOHAPATRA, S and MOHANTY, M. 2004. *Abuse and Activity Limitation: A Study on Domestic Violence Against Disabled Women in Orissa*. Oxfam. Bhubaneswar, India’.

to claim a sexual relationship with his wife, but is also able to control her and be violent towards her. These beliefs were not shaped by their experiences of living with disability, but by their experience of living as females in a conservative cultural context.<sup>199</sup>

199 GOYAL, N. 2017. Denial of sexual rights.

200 BADJENA, S.S. 2014. Sexual Violence Against Women with Disabilities and the Legislative Measures in India. Retrieved from <http://odisha.gov.in/e-magazine/Orissareview/2014/April-May/engpdf/46-57.pdf>

S.S. Badjena, in a 2014 article<sup>200</sup> looking at sexual violence against women with disabilities and legislative measures in India, presents a compilation of cases of sexual abuse of girls and women with disabilities. In her analysis of these cases she says:

In most cases, the victims of the crime **knew the accused** person prior to the commission of rape. In some cases they were raped by their own relatives including the father. The cases also suggest that most victims were raped **when they are alone and unprotected**. Most of the minor and child victims were allured and enticed by the adult accused. There are a whole lot of problems with how the testimony is read and assessed by the judges after it has been recorded, which cannot be addressed by legislation. In many cases disabled women are **unable to communicate** the act of sexual assault they face and even if they communicate, the **evidentiary value of their testimony are not taken seriously** either by the police or by the judicial system. As a result, even if the accused is convicted by the lower court, at the stage of appeal before Higher Court, the accused is acquitted owing to the non-recording of the prosecutrix's testimony or non-observance of the legal procedure by the court below. (emphasis added)

Further in her article, she covers legislative provisions under the new Criminal Law Amendment Act, 2013, to point out changes in the law applicable to a woman with disabilities. She notes, "There are no consolidation figures with regard to violence against women with disabilities. It would therefore be pertinent that when such cases are registered, crime against women with disabilities be also recorded as sub-category like in the case of crimes against women from scheduled castes, scheduled tribes etc."

She concludes by highlighting some important points:

Sexual Violence against disabled women is a silent act in our country because in majority cases women fail to realize they are victims or fail to communicate the act of violence. Even if it is communicated, seldom does it inspire belief. In most of the cases, it is found that the perpetrators are not brought to book. There is also fear that reporting the abuse could snap bonds with the caretakers. Lack of information and awareness is found by the fact that peer group learning is very limited amongst disabled women as they are less likely to be sent to school. The social role or the absence of a role attributed to women with disabilities, in conjunction with the stereotypes that exist, contribute to their vulnerability and lead to violation of their rights. Hence by way of legislating laws, state should not merely declare rights and entitlements but it should stipulate in detail the mechanisms by which rights can be realized.

The FST study with young people with disabilities found that about 17% or 14 respondents reported about being touched inappropriately by someone, which made them uncomfortable. Most of them reported such incidents occurring in the institute/organisation (7), followed by home (4). One of each group reported such experiences in the village, neighbourhood or at a friend's place. Out of the 14 respondents who reported having been touched inappropriately, 12 reported knowing the perpetrator. Half of those who experienced this, felt threatened by this experience. Further, only 8 respondents shared or discussed this experience with someone – 4 with his/her mother, 1 with his father, and 3 had shared the incident with their teacher/special educator. However, except two, none of the other confidantes had taken this report seriously and they had ignored, made fun of the incident or simply listened. The two care providers who did take some action reported it to the highest institute authority.<sup>201</sup>

It remains a disturbing fact that there are many care providers who have inadequate capacity to deal with these situations and who

201 FOUNDATION FOR SOCIAL TRANSFORMATION. 2016. *Understanding Sexual Health & Rights of Youth with Disabilities in Assam - A Study.*

are not trained, aware of, or sensitive to issues of abuse and the right of every individual to not be abused. The available research also reflects that people with disabilities, especially women with disabilities are at high risk of sexual abuse, quite often from their care providers.

Sameera Shamim points out that “Another critical reason for not reporting violence is the dependency that the victim may have for survival and care provision on the perpetrator.”

She continues, “What makes the situation worse is the belief of care providers and/or people with disabilities that it is ok to be abused. The vulnerability and dependence on the care provider often makes the abused and the abuser feel that the abuse is justified since care is being provided, leading to a vicious cycle of unending abuse. The lack of awareness and information amongst people with disabilities also plays out at another level where, if they happen to feel pleasure as a consequence of physical or sexual stimulation during abuse, they often feel guilty rather than realizing that it is actually abuse. Sometimes even if they do realize they are being abused, they do not mention or talk about it as they consider it to be their only avenue to experience sex.”

Given the prevalence of sexual abuse and parents’ fears about it, what is being done to prevent it? Unfortunately, focus tends to be on the unwanted consequences of abuse (such as pregnancy) rather than on the abuse itself and finding ways preventing it. For example, parents and care providers sometimes see hysterectomy as a way of protecting girls and women with disabilities from unwanted pregnancy. Hopefully, this practice will be stemmed because now the RPD Act, 2016, states “No person with disability shall be subject to any medical procedure which leads to infertility without his or her free and informed consent.”

More positive strategies like attempts to train disabled girls in self-defense, though important, are rarely thought of.<sup>202</sup> Sameera says, “Connecting girls and women with resources, spaces, services where

202 KHANNA, R., et al. 2004.  
Consultative Meet on Gender and  
Disability.

they can report or share their experiences is also very important as this will help them understand, and most importantly, speak about their trauma.”

Perhaps, because boys cannot get pregnant, there is so little attention paid to the sexual abuse of boys and men with disabilities. There are other populations and constituencies that are at particularly high risk of sexual violence but not enough focus is given to them, so these populations and their experiences are made invisible. Janet Price observes this in the context of disabled women, begging on the street and the sexual violence and rape they face. She also points out that women with disabilities in conflict areas or during migration / forced migration are particularly vulnerable to sexual violence.

Caregivers even in institutions mandated for the care of people with psychosocial or intellectual disabilities are also culpable of abuse, making this form of abuse institutional violence. As described in the report, *Treated Worse Than Animals*, Human Rights Watch documented cases of women and girls who had faced physical, sexual and verbal abuse at the hands of care providers in institutions, many of whom are not adequately trained. For example, staff use derogatory language such as ‘pagal’ (mad) or ‘mentally retarded’, perpetuating the social stigma against these women and girls. In 12 of the 24 institutions visited, residents or staff exploited women and girls with psychosocial or intellectual disabilities, forcing them to cook, clean toilets, or bathe other women with more severe disabilities. In the course of its visits to institutions, Human Rights Watch found 12 cases of verbal, 38 of physical, and 4 of sexual violence against women and girls with psychosocial or intellectual disabilities. While physical and verbal abuse is an everyday occurrence in every state-run institution and mental hospital that Human Rights Watch visited, sexual violence remains hidden as victims are less likely to talk about it.<sup>203</sup>

There are also instances of ‘medical abuse’. People with mental illness may not identify as persons with disabilities; indeed, they may go through months and even years without any disabling mental

203 HUMAN RIGHTS WATCH.  
2014. *Treated Worse than  
Animals*.

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. As Bhargavi Davar notes, “Anti-depressants and anti-psychotics impact people’s sexual expression and experience. People give up medication because of the impacts on bio-chemistry. But when labelled with a mental illness, your body is not considered as important as the illness and certainly sexuality becomes unimportant. “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. Dr. Lakshmi Ravikanth of The Banyan brings another viewpoint, saying, “It’s rather skewed to say that mental health institutions stifle sexuality related concerns (though this maybe prevalent); we must recognise that even family as an institution does the same in a more prolific manner. So it’s not about blame. We need to take into consideration that deeply personal expressions of sexuality especially for persons with disability exist within the framework of a societal fabric, and need to be operationalised via awareness, education, training, learning, media support, dialogues, in a compassionate manner, upholding the dignity of every person.”<sup>204</sup>

<sup>204</sup> Lakshmi Ravikanth. 2017. Personal communication.

## 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 false assumptions.

One common misconception is that disabled people are not sexually active and therefore not at risk of being infected. Another, that substance abuse, and sexual abuse and violence do not exist among disabled people and that none of them are homosexual or bisexual. These assumptions lead to the exclusion from HIV prevention and care services of a large group of individuals that face all the known risk factors for HIV equally if not more than do non-disabled individuals. Nora Groce led the Global Survey on HIV/AIDS and Disability for the World Bank and Yale University in 2004 and brought out a report called *HIV/AIDS and Disability: Capturing Hidden Voices*.<sup>205</sup> This survey 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, if not more vulnerable to all known risk factors. The lack of information and research on the inter-linkages 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.

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



In 2008 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,
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>206</sup>

206 GROCE N. E., TRASI R. and YOUSAFZAI A. 2008. Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts. The World Bank.. Retrieved from [https://www.ucl.ac.uk/lc-ccr/downloads/hivguidelines/HIV\\_Guidelines\\_on\\_Disability\\_-\\_World\\_Bank\\_-\\_ENGLIS.pdf](https://www.ucl.ac.uk/lc-ccr/downloads/hivguidelines/HIV_Guidelines_on_Disability_-_World_Bank_-_ENGLIS.pdf)

207 MOLL, K. 2007. *Too Few to Worry About? Or too Many to Ignore - The Exclusion of People with Disabilities from HIV Programmes in India*. Retrieved from <http://www.hivpolicy.org/Library/HPP001232.pdf>

208 CBM. 2014. Disability and HIV: Exploring awareness and vulnerability of people with disabilities in India. Retrieved from <http://www.cbmindia.org.in/Exploring-Disability-and-HIV-linkage-in-India-499643.php>

Building on Nora Groce's work, Kevan Moll's 2007 study on HIV and AIDS and disability in the Indian context estimates that according to the prevalence rate of HIV and AIDS in India given by the National AIDS Control Organisation (NACO) there were 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>207</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.

CBM, an international organisation working on issues of disability and inclusion, initiated a study conducted by FXB India Suraksha in 2013-14 across six states of India that found that poor awareness as well as lack of access to health care, and risk-taking behaviour, are characteristic features of the current status. The study also found that "In some cases people with disabilities are not even aware of their HIV status even after undergoing tests".<sup>208</sup> The states included in the study are Jharkhand, Gujarat, Manipur, Andhra

Pradesh, Mizoram and Madhya Pradesh. Of 386 participants, 58% were male and 42% female. A cross-disability approach was taken to include participants with visual, hearing, speech, locomotor and intellectual disabilities. This inclusion of intellectual disabilities is significant, creating space for widening the frame in which we tend to see impairment and disability. Findings of this CBM study have established that persons with disabilities are a constituency where too HIV and AIDS is prevalent, and low awareness, vulnerability and poverty increases the risk of HIV transmission for this group. More studies are required in this area. Treatment programmes are not reaching this group. People with disabilities need to be integrated into the design and plan of programmes focusing on HIV and AIDS and health care. The difficulty of access to infrastructure, resources and information that people with disabilities encounter due to existing attitudinal and environmental barriers is a primary reason for exclusion.

Thankfully, this is changing, at least in some parts of the world. The Africa Campaign on Disability and HIV and AIDS is addressing issues of the vulnerability of persons with disability who are infected or affected by HIV and AIDS. Working in partnership and collaboration mode, the campaign is described as being “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 equal access for persons with disabilities in Africa to information and services on HIV and AIDS; and undertake a coordinated response involving persons with disabilities in African countries to achieve inclusive national HIV and AIDS policies and programmes.”<sup>209</sup>

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>210</sup>

209 Africa Campaign on Disability and HIV and AIDS. Retrieved from <http://www.comunit.com/content/africa-campaign-disability-and-hiv-and-aids/>

210 Disability and HIV/AIDS. AIDS Free World Retrieved from <http://www.aidsfreeworld.org/our-issues/disability/resource-guide-aids-and-disability.aspx>

In India, too, Kevan Moll, who was cited above, 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>211</sup>

211 UNITED NATIONS OHCHR, WORLD HEALTH ORGANISATION & UNAIDS. 2009. Disability and HIV Policy Brief. Retrieved from [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)

212 SINGH, S. 2015. India's AIDS response: the missing voices of persons with disabilities. *RHIME*. 2015;2:3-10. Retrieved from [https://www.rhime.in/ojs/index.php?journal=rhime&page=article&op=view&path%5B%5D=39&path%5B%5D=pdf\\_11](https://www.rhime.in/ojs/index.php?journal=rhime&page=article&op=view&path%5B%5D=39&path%5B%5D=pdf_11)

In a 2015 journal article on India's response to AIDS, Dr. S Singh titles a section of the article 'The missing voices in India'.<sup>212</sup> In this section he observes, "The fourth phase of the National AIDS Control Programme (NACP-IV) 2012–2017 was launched with the key strategy to intensify and consolidate prevention services with a focus on high risk groups and vulnerable populations. Sadly, NACP-IV does not have any working group on disability. The NACO annual report of 2013-14 does not feature a single word with 'disability' or 'persons with disabilities'." Singh cites the 2014 UNAIDS Gap report that says that India has the third largest number of people living with HIV in the world. He goes on to say, "The UNAIDS Gap report has identified twelve risk groups that are especially vulnerable and have been left behind from the national AIDS response. Of these twelve, one is persons with disabilities."

According to the 2014 Gap Report referred to by Singh in his article, China, India, Indonesia, Myanmar, Thailand, and Vietnam account for more than 90% of the people living with HIV in Asia and the Pacific region.<sup>213</sup> The report speaks of the limited data available on HIV and AIDS prevalence amongst people with disabilities but does say that based on available information, this prevalence is about the same, or even higher, than in persons without disabilities. Further in the report it is stated:

213 UNAIDS. *The Gap Report*. 2014. Geneva. Retrieved from [http://files.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS\\_Gap\\_report\\_en.pdf](http://files.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf)

HIV services are needed both for people with disabilities who acquire HIV or who are at risk of HIV infection. Services must also respond to the needs of people living with HIV, who then develop disabilities as a result of the progression of HIV or due to the side-effects of antiretroviral therapy. Many health practitioners lack the necessary knowledge, skills and resources to provide these accessible, appropriate services. Thus, better training is needed and peer support will help to close this gap.

The report also states that, “People with disabilities should be fully included in national HIV responses. National strategic plans on HIV must include good practice on disability. HIV must also be included as an integral part of disability rights strategies, initiatives and programmes.”

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.

While reviewing this paper, Janet Price observed that in other countries, statistics indicated higher levels of HIV infection amongst deaf people due to challenges in accessing information on HIV and also higher levels of sexual violence. Such highly disaggregated disability and HIV statistics are crucial to help design HIV prevention programmes and guidelines, but are not easily accessible. Some efforts have been made though findings may not be used to generalise across large populations due to the limitations of these studies. In a 2007 study in Manipur and Nagaland, the researchers concentrated on studying HIV programmes using the lens of disability inclusiveness. There is some reference to the finding

that certain types of impairment are associated with increased vulnerability and higher levels of HIV risk. The researchers state:

This research among PWD and providers of disability and HIV programmes in Manipur and Nagaland found that participants perceive PWD to be vulnerable to HIV infection, but the level of vulnerability or risk depends upon type and severity of impairment, gender and socioeconomic circumstances.

The researchers also state that:

The embarrassment shown in discussing this topic even within same-sex group discussions, and the absence of reference by PWD to male-male sex, points to the need for explicit messages about risk practices. As most HIV prevention materials use indirect language and do not touch upon the most sensitive topics, such as male-male sex and sexual abuse, there are worrying gaps for PWD. Given the reality of sexual abuse of PWD (especially the hearing- and intellectually-impaired), it is essential that the wider community recognise its role in protection and prevention.<sup>214</sup>

214 MORROW et al; 2007. Fostering disability-inclusive HIV/AIDS programmes in northeast India: a participatory study. *BMC Public Health*.2007; 7: 125. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1924853/>

Singh, in the article cited earlier, also recommends:

Efforts should be made to estimate the prevalence of HIV among persons with disabilities. A realistic estimate will permit targeted and continuous supply of resources. When including disability questions in the existing surveys, care should be taken to use impairment-specific and disaggregated indicators. Additional data should be collected on determinants so as to link disability with Sustainable Development Goals.<sup>215</sup>

215 SINGH, S. 2015. India's AIDS response.

## REPRODUCTIVE HEALTH AND RIGHTS

### Menstruation

Menstruation and menstrual management create a lot of anxiety for women/girls with disabilities. Parents and care providers worry greatly about how they will cope with menstruation and sexuality when their disabled daughters reach menarche.<sup>216</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 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. Such is the shame around it that 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.

In 2015, the organisation Aaina, working in Odisha, prepared a report on the ‘Viability of Low Cost Menstrual Absorbent in Odisha with a Special Focus on Women and Girls with Disabilities’<sup>217</sup> which presents useful facts and data. One of the findings of the study is that “Only 37 percent adolescent girls and 24 percent adolescent

<sup>216</sup> KHANNA, R., et al. 2004. Consultative Meet on Gender and Disability.

<sup>217</sup> CHOUDHURY, S. 2015. *Viability of Low Cost Menstrual Absorbent in Odisha with a Special Focus on Women and Girls with Disabilities*. Retrieved from <http://aaina.org.in/Doc/MenstrualAbsorbent-Odisha.pdf>

girls with disability were aware about menarche and friends are the main source of information.” In a specific section focusing on girls with disabilities, the report lists issues that include – physical discomfort caused by stiffness and orthopaedic impairment or cerebral palsy, when trying to use cloth or pads during menstruation, parental concerns of safety and menstruation management leading to looking at the option of operation (surgical intervention such as hysterectomy), and improved design of menstrual absorbents to avoid leakage etc. specially when being used by a person with restricted mobility.

Parents and care providers look for ways in which menstruation can be managed more easily for girls/women with disabilities. The issues and concerns are often seen as being 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. Renu Khanna, while drawing from the WOHTRAC consultative meeting on gender and disability, said, “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, on the basis of her experiences working with people with visual impairment, finds that some students with visual impairments may 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.

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 travelling 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 travelling or when out for work.”

This aspect also impacts the education of girls with disabilities. The lack of proper and adequate support and facilities to maintain menstrual hygiene, including the lack of trained care providers who may be required for personal assistance, forces girls with disabilities to drop out of school upon reaching puberty. Another significant factor is the lack of accessible toilets, separate for female from male [as] this is the time that sees the big dropout of disabled girls from school, if they have even managed to attend. This is true of girls in other institutions like vocational training centres as well.

In a 2014 interview, Anjlee Agarwal, the Director of Delhi-based Samarthyam, National Centre for Accessible Environments said:

In our audits with 500 schools in 16 states, we found that less than 60 schools have toilets for girls, which means around 440 schools do not have toilets. Few which are available do not have doors, lights, water and even ventilation. So, the girls defecate in the open in the school premises, compound areas or use the boys’ toilet. In the boys’ toilet, they are scared that there is a man or a boy approaching because most of the male teachers also use the boy’s toilet.

When they attain puberty or start menstruating, they drop out of school due to lack of water and menstruation hygiene management. Disabled girls are the biggest sufferers, because they can’t do anything on their own, they cannot even squat like other girls. Less than 0.1 % girls with disabilities in the



218 SHARMA, M. (2014, November 19). India lacks access to toilets for disabled women, highlights social activist Anjlee Agarwal. *DNA India*. Retrieved from <http://www.dnaindia.com/locality/north-west-delhi/india-lacks-access-toilets-disabled-women-highlights-social-activist-anjlee-agarwal-46545>

219 Ibid.

schools get to access toilets and less than 0.5% stay in the schools after hitting puberty. The families ask them to stay back at home for 5 days a week, hence, 60 days of the school are left out.<sup>218</sup>

In the same interview, Anjlee makes a strong point of great significance to issues of inclusion:

We are working with the Ministry of Urban Development, we worked out the model building bylaws. In the model building bylaws, we enforced that accessible toilets or disable friendly toilet should not be just a toilet but it should be used as a multi-use toilet, where the senior citizens, pregnant ladies, people having medical conditions and even families with young people can use it because these toilets are bigger, spacious, so you can even provide a diaper changing table and all that to make it like a family toilet. There is multi-fold use of this toilet and it will not be locked and it would not be closed and used as a storage system. Even the access to these toilets must be easy, with illumination, even pathway must be provided.<sup>219</sup>

A space and facility that is accessible to many different service users, is therefore not a space that segregates and isolates a specific group of people. By bringing in the concept of 'multi-use', inclusion becomes an implementable reality.

## 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 are 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 (but their partner can help them wear one). Sponges, diaphragms, female condoms and oestrogen-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 oestrogen, 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. Several experts and women's rights activists oppose the introduction of DMPA on account of adverse side effects while others believe that it is a good option.<sup>220</sup>

In 2017, while we were updating this paper, Abha Ketarpal shared with us an experience from some of her interactions with persons with disabilities who approach her with questions and issues:

Three years ago, a lady aged around 32, approached me online. She has locomotor disability because of polio and uses a wheelchair. She works as a manager in a reputed government bank. She was proposed to by a man online. They started dating online and sometimes they would meet in person. The man, after some months, proposed marriage. After that the families met and they got married. Before her marriage she consulted me regarding sexual issues. She seemed quite nervous and worried. She asked me if she would be able to conceive or not because of her disability. I assured her that her locomotor disability was not likely to come in the way of her

220 RAO, M. (2016. April 11). The two serious problems with India's new family planning push. *Scroll.in*. Retrieved from <https://scroll.in/pulse/806365/the-two-serious-problems-with-indias-new-family-planning-push> and Counterview.org. (2015. September 24). Withdraw decision to allow injectable contraceptives, they increase risk of women and their partners to be infected with HIV. Retrieved from <https://counterview.org/2015/09/24/withdraw-decision-to-allow-injectable-contraceptives-they-increase-risk-of-women-and-their-partners-to-be-infected-with-hiv/>

conceiving. But she did not want to get pregnant immediately after marriage. Her fiancé made her very clear that he won't be using condoms as it would decrease his pleasure. He told her that she could take contraceptive pills to prevent pregnancy. I told her not to start taking pills herself. Women with locomotor disabilities have to consult a doctor before taking pills. Mobility must be assessed in terms of increased risk of venous thromboembolism when considering hormonal contraception that contains estrogen. So after her marriage she went to a gynecologist and started having some pills after undergoing some blood tests and other check-ups. Now she has a little daughter and is happy with her family life.

On the issue of whether it is possible for unmarried women with disabilities in India to seek contraceptive advice, Abha Khetarpal observes that "For unmarried girls in our country such counseling is rarely available. If they visit a gynecologist just before their marriage they might get some information. Otherwise they are mostly uninformed and misinformed."

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 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 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. Having said this, it is worth noting that a large number of women with disabilities may have children, especially if they acquired a disability after marriage. Also, some men may prefer to marry women with disabilities due to other complex issues they may experience, such as for example, experiencing disability themselves, or being an older person (single, but senior) or other such reasons of personal circumstance.

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 could 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.

In a 2014 report of the findings of the South India Disability Evidence (SIDE) study of 2012, the researchers concluded that “Women with disability have a significantly lower pregnancy rate compared to women without a disability. Women with disability have significantly higher risk of co-morbidities like diabetes and depression. Contrary to what has been reported from many countries, parameters related to antenatal and natal care were similar for women with and without a disability.”<sup>221</sup> 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.

221 MURTHY, G.V., JOHN, N. SAGAR, J. 2014. South India Disability Evidence Study Group. Reproductive health of women with and without disabilities in South India, the SIDE study (South India Disability Evidence) study: a case control study. *BMC Womens Health*. 2014; 14: 146. Published online 2014 Nov 30. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4256815/>

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>222</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.”

Internet blogger Heather Lindsey<sup>223</sup> was born with Athetoid Cerebral Palsy. As she writes from her own experiences on her blogsite, she says that when she and her husband were thinking of having children, the first thing she did was look for parenting experiences shared by women with disabilities, but she couldn’t find much of anything. As she wrote:

I wanted to learn about what it was like to go through pregnancy for someone with a physical disability. I wanted to learn about adaptive equipment out there that would make it easier for me to care for a baby. I wanted to hear about other disabled mothers’ tricks that made things easier for them. I wanted to know that someone else went through this and succeeded. I wanted personal stories.<sup>224</sup>

So she started writing and sharing her own experiences from 2010. She is a mother of two children.

In a 2011 online article, the author, Erin Andrews, a rehabilitation psychologist who is also a congenital triple amputee, writes of her experience of pregnancy and says that her regular gynaecologist did not handle her case and was perhaps uncomfortable with the idea of her getting pregnant. About some of the issues she faced, Erin wrote:

Normal physical effects of pregnancy can affect a woman’s disability. The impact of bodily changes is dependent on the specific type of disability and the individual woman. For example, the weight gain and altered body habitus associated with pregnancy can influence a woman’s mobility, ability to

222 SLAVIN, A. (2009. August 8). I’m blind – and I’m a good mother. *The Guardian*. Retrieved from <http://www.guardian.co.uk/lifeandstyle/2009/aug/08/blind-motherhood-disability>

223 LINDSEY, H. Raising a Child as a Disabled Mother – The Joys, Challenges, and Victories. Retrieved from <http://thelindseyohana.blogspot.in/p/home.html>

224 LINDSEY, H. Raising a Child as a Disabled Mother – The Joys, Challenges, and Victories. Retrieved from <http://thelindseyohana.blogspot.in/p/about-this-blog.html>

transfer, and her overall independence. Early on, I figured I would simply adapt to these changes and didn't anticipate them to be problematic. Later, I experienced serious discomfort and skin integrity compromise sitting in my wheelchair due to the changes in my weight distribution. This necessitated that I obtain a seat cushion designed to distribute pressure more evenly; the downside was that this cushion made lower body dressing difficult for me. Transferring in and out of my wheelchair has become progressively more difficult. The physical changes of pregnancy have been substantial, and have affected my physical functioning much more than I had anticipated.<sup>225</sup>

225 ANDREWS, E.E. 2011. Pregnancy with a physical disability: One psychologist's journey. *Spotlight on Disability Newsletter* | December 2011. Retrieved from <http://www.apa.org/pi/disability/resources/publications/newsletter/2011/12/pregnancy-disability.aspx>

She ends her piece by considering the meaning of independent living, giving her understanding of the term in the context of autonomy and control over one's own life, and she speaks of the importance of support and assistance on a journey such as hers. We are still to find accounts such as this in the Indian context.

The Internet does provide a platform for many who are able to access and use it, to share stories and experiences. It is still however, not accessible to a vast majority and those are the stories that are mostly unheard, quite often unvoiced. It is a challenge finding voices from India describing pregnancy as experienced by a person with a 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."

Janet Price flags another issue of importance to consider in this

discussion – that of women with congenital disabilities, or women married to men who may have such disabilities. As Marge Berer says in an open letter, a pregnant woman needs to know if the foetus she is carrying has one or more anomalies, so as to be able to decide “whether this is a pregnancy and potentially a child who, she can cope with for the rest of her life. She has to take into account her own, her partner’s and her existing children’s life circumstances, and whether she will get any support to do so.”<sup>226</sup> While it is beyond the scope of this paper to build and present an understanding of this aspect, it is important to debate the need for, and the absence of, genetic counselling and screening facilities in India.

## Abortion

Upholding the UNCRPD and basic human rights principles, married and unmarried women with disabilities must have access to safe abortion services. There are 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.

226 BERER, M. 2017. Open Letter to the Committee on the Rights of Persons with Disabilities. International Campaign for Women’s Rights to safe Abortion. Retrieved from <http://www.safeabortionwomensright.org/open-letter-to-the-special-rapporteur-and-committee-on-the-rights-of-persons-with-disabilities/>



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>227</sup>

227 [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)

228 UNFPA. 2011. Trends in selective abortions of girls in India. Retrieved from <http://www.unfpa.org/resources/trends-selective-abortions-girls-india>

229 UNFPA. 2011. Trends in selective abortions of girls in India: analysis of nationally representative birth histories from 1990 to 2005 and census data from 1991 to 2011. Retrieved from [http://www.unfpa.org/sites/default/files/resource-pdf/UNFPA\\_Publication-39857.pdf](http://www.unfpa.org/sites/default/files/resource-pdf/UNFPA_Publication-39857.pdf)

230 GOVERNMENT OF INDIA. Pre-Conception & Pre-Natal Diagnostic Techniques (Prohibition of Sex Selection) Act, 1994. Retrieved from <http://pndt.gov.in/index2.asp?slid=49&sublinkid=31>

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

A 2011 UNFPA report<sup>228</sup> studying the number imbalance between girls and boys in the age group of 0-6 years has found that “Selective abortion of girls, especially for pregnancies after a firstborn girl, has increased substantially in India. Most of India’s population now live in states where selective abortion of girls is common.”<sup>229</sup>

The Pre-Conception and Pre-Natal Diagnostic Techniques (Prohibition of Sex Selection) Act, 1994<sup>230</sup> or PC-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 Rachana 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>231</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?”

Again, 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), promises that by eliminating disability, society will be freed of the responsibility of caring for those with different abilities and needs. (Janet Price responds to this saying that this is a spurious argument because “many/most PwD will acquire their disability during life, not be born with it.”) Another message is that good parents will get tested: only irresponsible parents will allow disabled children to be born.<sup>232</sup>

When it comes to abortion internationally, it may seem as if reproductive rights and disability rights are in conflict. Many disability rights activists oppose abortion on the grounds of foetal anomalies. Anti-abortion activists use the language of disability rights to oppose abortion. Pro-abortion activists fear that this will slide into language that gives rights to the unborn and restrict women’s reproductive choices. In November 2017, Marge Berer, an abortion rights activist from the UK, wrote an open letter to the Committee on the Rights of Persons with Disabilities. In the letter, she presents her detailed responses regarding the observations and recommendations (specifically related to abortion) in the “Concluding observations on the report of the UK to the Committee on the Rights of Persons with Disabilities” made in the UK in August 2017. She begins the letter by focusing on the definition of ‘a person’, analyses reasons for abortion, legal approaches to abortion, decision

232 SANDHYASRINIVASAN (Editor). 2010. *Making Babies: Birth Markets and Assisted Reproductive Technologies in India*. Zubaan and SAMA-Resource Centre for Women and Health, New Delhi.

making about pregnancy, and women's autonomy. She addresses the debate on foetal rights and the question of the 'abilities' of a foetus. She writes that – "An embryo/foetus has no 'abilities' of its own. Its life and development are utterly dependent on the woman carrying it. Disability (and ability) are conditions that come into existence only after birth."<sup>233</sup> There are passionate, personal and political sides to these debates and the fact remains that this is a complex issue with many ethical and emotional ramifications.

233 BERER, M. 2017. Open Letter to the Committee on the Rights of Persons with Disabilities. International Campaign for Women's Rights to safe Abortion. Retrieved from <http://www.safeabortionwomensright.org/open-letter-to-the-special-rapporteur-and-committee-on-the-rights-of-persons-with-disabilities/>

Closer home in India, we have seen this issue play out in multiple situations.

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 furious national debate in India almost a decade ago. Niketa Mehta approached the court in 2008 to abort her 26 week old foetus detected with a congenital heart defect.<sup>234</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 women should not seek an abortion on grounds of foetal anomalies. On the other hand, many people feel that in the case of future severe disabilities that might place strains, including emotional and financial ones, on the family, it is up to the woman to decide. As Neha Madhiwalla put it in an article about Niketa Mehta's dilemma, "I argue that the value of living persons cannot be equated with the foetus which is not a person. Thus, the right of a woman to decide on the fate of her pregnancy does not conflict with, or interfere with, the human rights of the disabled".<sup>235</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.

234 VENKATESAN, J. (2009. February 15). Supreme Court Notice to Centre Over Abortion Law. *The Hindu*. Retrieved from <http://www.thehindu.com/todays-paper/tp-national/Supreme-Court-notice-to-Centre-over-abortion-law/article16334225.ece>

235 MADHIWALLA N. 2008. The Niketa Mehta Case: Does the Right to Abortion Threaten Disability Rights? *Indian Journal of Medical Ethics*. Retrieved from <http://ijme.in/articles/the-niketa-mehta-case-does-the-right-to-abortion-threaten-disability-rights/?galley=html>

Who then has the right to decide whether a pregnancy that involves

a foetal anomaly should be carried to term 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 fetuses?"<sup>236</sup>

236 GHAI, A. and JOHRI, R.  
2008. *Prenatal Diagnosis: Where Do We Draw the Line?*

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 (which cannot be predicted at the prenatal stage and is not a predictor of how the disability will manifest within the body after birth), or 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>237</sup> Janet Price adds, "Many disabled people also argue that experience matters and that disabled people with the condition and/or parents raising a child with that diagnosis should be involved in any pre-abortion counselling."

237 Ibid.

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>238</sup> This ruling has raised mixed responses amongst the disability, health, sexuality and reproductive rights 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 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.

Implementation of the law is required to be responsive to nuances. In 2015 the Supreme Court allowed a minor, survivor of rape, to abort the pregnancy that resulted from that rape, though the foetus was 25 weeks old. In doing so, the court overturned the judgement of a High Court that had not granted permission.<sup>239</sup> In 2016, the Supreme Court granted permission for abortion of a 24-week-old foetus to another survivor of rape, this time including in the consideration of the case, the fact that the foetus had congenital anomalies.<sup>240</sup> However, also in 2016, a medical panel refused permission to another survivor of rape, a 14 year old with a 33-week pregnancy. Her case took four months to reach the panel and in those months, an FIR and multiple appeals were filed with legal and judicial authorities.<sup>241</sup> While there

238 TNN. (2009. July 22). SC Says No to Termination of Victim's Pregnancy. *The Times of India*. Retrieved from <http://timesofindia.indiatimes.com/article/show/msid-4804983,prtpage-1.cms>

239 BEDI, P. (2016. August 8). It is Time to Overhaul India's Restrictive Abortion Law. *The Wire*. Retrieved from <https://thewire.in/57111/how-indias-abortion-laws-fail-its-women/>

240 GHOSH, A. (2016. July 26). MTP Act: What 45-year-old abortion law says, why it must change. *The Indian Express*. Retrieved from <http://indianexpress.com/article/explained/abortion-law-rape-victim-terminate-pregnancy-supreme-court-20-weeks-pregnant-2935481/>

241 THE QUINT. (2016. September 19). How We Failed the 14-Year-Old Pregnant Rape Survivor in Bareilly. Retrieved from <https://www.thequint.com/fighting-rape/2016/09/17/how-we-failed-the-14-year-old-pregnant-rape-survivor-in-bareilly-court-cmo-judiciary-hospital>

was still time for a safe termination of pregnancy, these authorities did not grant permission.

Thus, the situation is entangled in debate, made more complex by the urgency of timeline in each individual case as the passage of the days and weeks does not support the time needed for such debate. Further, the resolution in each case is highly dependent on the responsiveness of the officials at various medico-legal positions, before whom these cases are heard.

## Hysterectomy

As noted earlier in this paper, in India the new RPD Act has been passed and it contains provisions that protect the right of women with disabilities from medical procedures that may lead to infertility, without informed consent. This is a significant step forward as a rights based approach to legislation. Implementation of the law is a challenge as it will take multiple different kinds of efforts with many different groups of people, before widespread awareness and acceptance as well as compliance with the law is achieved.

Hysterectomy is viewed and used as a solution to the ‘problem’ of menstruation and sexual abuse of women with disabilities. It is well known that 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 to their children after they die.<sup>242</sup>

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>243</sup> This

242 KHANNA, R., et al. 2004. Consultative Meet on Gender and Disability.

243 STREE KRUTI, SHRAMAJEEVIKA, FORUM FOR WOMEN’S HEALTH. FORUM AGAINST OPPRESSION OF WOMEN, LOKASHAHI HAKK SANGHATANA, LAL, R. & KANGA, M. 1994. *In the Guise of Human Dignity. Fact-finding report*. Retrieved from <http://www.unipune.ac.in/snc/cssh/humanrights/07%20STATE%20AND%20GENDER/12.pdf>

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>244</sup>

244 KHANNA, R., et al. 2004. Consultative Meet on Gender and Disability.

245 SREEDHARAN, D. (2013. August 4). The silenced wombs. *The Hindu*. Retrieved from <http://www.thehindu.com/features/the-yin-thing/the-silenced-wombs/article4985813.ece>

A 2013 news article<sup>245</sup> presented the case of an 18-year-old girl with cerebral palsy who, with the support of her family, particularly her mother, leads a life of choices and options much like any other teen, active on social media, attending school, and importantly, managing her self-care including menstrual hygiene needs by herself. As the author of this piece discovered, just eight years prior to this, doctors had suggested to her mother that she gets a hysterectomy done for the then 10-year-old, to avoid the problems that would occur at puberty. This mother, Farida Rizwan, refused. Farida is an active blogger and is also a breast cancer survivor. In a 2013 blog post, she writes:

Talking to few parents, what I have learned recently is very shocking. Most of the girls with disability go through hysterectomy so that they do not have to deal with their menstruation. The girl cannot say anything; the government does not want to say anything about this. Is it fair on part of doctors, parents and society to just remove an organ from the girl’s body so that the situation is convenient for everyone? I have personally heard from a mother that hysterectomy is necessary for her intellectually challenged daughter because pregnancy could lead to social stigma. This is a shocking revelation for me. Does that mean that the parents are already prepared for the abuse the girl may go through?<sup>246</sup>

246 RIZWAN, F. 2013. Bangalore for Women with Special Needs. Retrieved from <http://www.chaptersfrommylife.com/search?q=Menstruation>

Many parents continue to consider the option of hysterectomy without the understanding and informed consent of their child with

a disability. In a 2017 article, Jhilmil Breckenridge says, “To date, guardians and parents stealthily take their daughters to hospitals and get them sterilised; getting consent is not even considered necessary. In addition, mentally ill persons are often considered hyper-sexual and this is considered funny by so called ‘normal’ people.”<sup>247</sup>

247 BRECKENRIDGE, J. 2017.  
People with mental illnesses.

The reality is that hysterectomy is not a ‘solution’. Menstrual management is teachable in a majority of situations. 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 their 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 from becoming 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:

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>248</sup>

<sup>248</sup> GHAI, A. 2003. *(Dis) Embodied Form*.

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 other citizens.

It is difficult to find information on adoption by parents with disabilities in India. On the website [sexualityanddisability.org](http://www.sexualityanddisability.org), there are some questions and responses related to adoption.<sup>249</sup> A lawyer and solicitor from Mumbai, Kanchan Pamnani, who is visually impaired, is quoted on the site as saying:

The law speaks about the 'welfare of the child' and the

<sup>249</sup> POINT OF VIEW. Adopting a child – Sexuality and Disability. Retrieved from <http://www.sexualityanddisability.org/having-children/adopting-a-child/>

interpretation by the administrators is that the welfare of the child would not be served if there is a disabled person adopting...I know at least two recent cases where one of the disabled parents is visually challenged. They were first discouraged by adoption agencies and then when force and influence was used, relented.

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, and The Guardians and Wards Act, 1890 which 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 the clause that mentions 'sound mind', which can be interpreted to exclude people with intellectual disabilities and mental illness and therefore can be discriminatory.<sup>250</sup>

In, January 2017, the Ministry of Women and Child Development (MWCD), Government of India, notified new Adoption Regulations, available on the website of Central Adoption Resource Authority (CARA).<sup>251</sup> The first of the criteria for eligibility of prospective adoptive parents is that they should be physically, mentally and emotionally stable, financially capable and should not have any life threatening medical condition. The terms 'physically, mentally and emotionally stable' are not defined.

While the forms and formats provided under these Regulations do cover medical and health issues and conditions, including questions on emotional, physical, psychiatric and psychological status of prospective parents, and also the medical conditions of the children who are available for adoption, there are no clear guidelines on adoption *by* people with disabilities. Further exploration of this, though beyond the present scope of this working paper, is crucial to policy and advocacy measures that aim to uphold disability rights. It will be interesting to see if the RPD Act<sup>252</sup> that specifies the right

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

251 CARA - <http://www.cara.nic.in/#> Ministry of Women and Child Development Notification. 2017. Adoption regulations. [http://www.cara.nic.in/PDF/Regulation\\_english.pdf](http://www.cara.nic.in/PDF/Regulation_english.pdf)

252 GOVERNMENT OF INDIA. Rights of Persons with Disabilities Act 2016. Retrieved from <http://www.disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf>

to equality, non-discrimination and legal recognition of persons with disabilities could be used to challenge some of the criteria and processes determining who is eligible to adopt.

# SOME POINTERS TO THE WAY AHEAD

Despite the many challenges outlined earlier, there are positive stories too that indicate possible directions to take forward the work on sexuality and disability. 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 SRHR 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 and of working with people with disabilities.<sup>253</sup> In this section are examples of initiatives that have already begun as well as some suggestions for what can be done.

## Skills and Training

Listening to the voices of persons with disabilities is key to identifying a way forward. These voices reflect a personal understanding of sexuality, of relationships, of attitudes that prevail in the socio-cultural environment, and most importantly, of what they want.<sup>254</sup> The FST report documents thoughts of the young people who were part of their study:

253 DISABILITY AND SOCIETY. Retrieved from [http:// http://www.tandfonline.com/toc/cdso20/current](http://http://www.tandfonline.com/toc/cdso20/current) and SEXUALITY AND DISABILITY. Retrieved from <http://www.springer.com/psychology/community+environmental+psychology/journal/11195>

254 FOUNDATION FOR SOCIAL TRANSFORMATION. 2016. *Understanding Sexual Health & Rights of Youth with Disabilities in Assam – A Study.*

“I feel our limitation makes people laugh at us. I want our development, want people to understand us”

“Except for our lack of vision everything is same like able bodied people. People should not laugh at us due to our disability because we all are equal”

“Both men and women are different and their hormonal change makes them more sexually active. So it is essential to give them knowledge on it. Socialization process is the main reason for our limitations”

“I feel it is essential to impart knowledge on sex education for severe ID [Intellectual Disability] cases”

“It is necessary to teach girls about safety, safe touch and unsafe touch”

“I like my caregiver because she loves me a lot, more than others. She helps me during periods. She helps me to dress up”

Adolescents with disabilities have similar experiences and requirements as any young person undergoing similar physical and emotions changes. It is important to acknowledge this reality and address these concerns rather than continue to be silent around them. But most often, when confronted with these concerns as the children with disabilities in their care are growing up, parents and caregivers do not know what to do. They face a lot of anxiety and have many questions themselves, but often they try and ignore these concerns as they do not know how to handle them or resolve them. There is a pressing need to equip parents and other care providers with information and skills to address sexuality, SRHR related issues. It is heartening to note that more and more workshops and sessions are being organised for parents and care providers.

At one such workshop with parents and care providers facilitated by Shampa Sengupta at a Kolkata school, the school principal introduced the workshop thus, “We are taught to believe that sexuality is a taboo topic for discussion, but children find surreptitious ways of drawing information on sex and sexuality through peer groups,

books and films. However, what about children with ‘special needs’? For example, how and where does an autistic child find this supportive peer group for information? Isn’t her journey towards discovering her sexual self a solitary one? Therefore it is all the more important for parents and educators of such children to feel free and let go of their inhibitions to have a frank dialogue. This is about the emotional and sexual wellbeing of their wards.”<sup>255</sup>

255 Shampa Sengupta. 2015.  
Personal communication.

One of the frequent questions and concerns of parents and care providers that invariably emerges during workshops such as these, relates to an aspect of sexuality that causes embarrassment and extreme discomfort – that of masturbation. As Shampa recounts in the workshop report, “The very first question was from an educator who said that it becomes difficult for teachers to explain masturbation techniques to grown up students even though they know that if the students do not pleasure themselves, often their behavioural disorders get aggravated. How could the teachers communicate with the parents to ensure that they train their children?” The topic of masturbation remains an area of stress and difficulty. Activists, educators and resource persons such as Shampa include space for such discussions in their workshops and emphasize that there is no single answer to fit all.

At the same time, it is important to create a framework that can be used for education, awareness and skills building, in the same way as for any other subject. One such illustration of a possible framework is described in the workshop report as, “For example, a teacher might teach an adolescent boy how to eat with a spoon. This is part of the teaching curriculum. But the boy spends only 4 to 5 hours of the day at school while the rest of the day, he is at home. So even if he learns to use the spoon slowly, the effect may be nil if at home somebody feeds him. So for him to be self reliant, the skills being taught at school should be harnessed at home as well. For this, the parents and teachers need to come to a common understanding. Similarly for masturbation. Where and how to masturbate should be lessons that can become part of the curriculum like other issues and for this parents and teachers need to come together.” This

makes an important point. Rather than ignore the uncomfortable, it is crucial that people come together and work out constructive, creative strategies guided by a rights based, affirmative approach to sexuality.

Another point to keep in mind while working with parents and care providers is that it is important that gender roles and stereotypes are questioned. At workshops for parents, an oft-recurring theme is that more women tend to attend than men; it is assumed that mothers are responsible for the care and parental engagement involved in raising a child.

An area of special concern for parents and care providers of girls and women is that of menstruation. Several organisations already include sessions on menstrual management, genital hygiene and socially appropriate sexual behaviour. As far back as three decades ago, The Family Planning Association of India (FPAI) 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. In 2005, Renu Adhlakha 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*.

Apart from menstruation, issues of sexual expression are often difficult for families to address. And, apart from parents, staff in institutions and organisations that work with people with disabilities are another group of people who are quite often at a loss when it comes to dealing with issues of sexuality. One of the respondents quoted in the 2016 CREA report “spoke of the sort of dilemmas that present themselves, saying, ‘If that person wants to marry, or have a relationship or wants to masturbate.... how we are responsible and how they are responsible ... both sides need to be articulated. It is not that I am a spokesperson for her needs. I am listening yes. But we should also be able to provide a space to address what she can

do with her needs. Should we decide that? Or should the individual decide, in connection with the component of responsibility that I mentioned earlier? This is something that needs to be thought about”, and also, “Because how much to train and how to train is a difficult and complicated subject. Many individuals may be at an intellectual age of a child and then we should sort out how much one can impart to them.”<sup>256</sup>

The report goes on to say:

Work with women with psychosocial disabilities, specifically around sexuality is at a nascent stage and challenging. As the team goes forward in this work, workable solutions need to be found to conduct trainings with this constituency of women. This means providing information in a way that is comprehensible to the group of women being trained. This also means grappling with questions of ‘space for sexual expression’, especially with women living in Institutions, which have come out quite clearly through the needs assessment exercise.

These are very real issues that organisations and staff on the ground face.

The report points to three key constituencies that require priority focus of training and knowledge and capacity building programmes on SRHR: Women with Disabilities; Parents of disabled children; and, Teachers and special educators, organisations and institutional staff. The thematic areas that are seen by respondents as priorities for training and knowledge dissemination are: Body, Body Image and Self Esteem; Sexuality education; Reproductive system; Puberty and menstruation; and, Sexual harassment, domestic violence and sexual assault.

While all these themes are important for designing training curricula, it goes without saying that any such content listing needs to be comprehensive and include multiple other focus areas such as contraception, abortion, HIV and AIDS, marriage and relationships,

<sup>256</sup> CREA, ANJALI MENTAL HEALTH RIGHTS ORGANISATION, POINT OF VIEW, EQUALS CENTRE FOR PROMOTION OF SOCIAL JUSTICE and SRUTI DISABILITY RIGHTS CENTRE *Needs Assessment Report- Addressing Disability and Sexuality Rights, Closing the Gap – Building Institutional Capacity to Address Sexuality and Disability. (2016) (Unpublished Draft).*



gender and sexual identity, choice and pleasure.

257 FOUNDATION FOR SOCIAL TRANSFORMATION. 2016. *Understanding Sexual Health & Rights of Youth. with Disabilities in Assam - A Study.*

The FST report also specifies the need to develop training modules for teachers on sexuality as well as a special manual for communicating with young people with disabilities on sexual and reproductive health issues.<sup>257</sup> This is an important and distinct requirement, separate from the creation of training content, because communication strategies and skills are crucial to any engagement between resource people or care providers and people with disabilities who are at varying levels of support needs and capacities. It must be understood that these various levels of support needs are due to a combination of many factors including not only the impairment or disability that an individual may experience, but also the education, engagement experience, and support or assistance that the individual has access to in their life.

The perspective with which these issues are approached is also very important. Choice and pleasure must be addressed as also protection from infection, unwanted pregnancy, abuse and violence. Looking at the intersection of disability and sexuality, Nidhi Goyal remembers that in 2011 the work on this theme was restricted, there was much that people were not talking about. When she began working with Point of View on the sexuality and disability website, it was unexplored territory. She recalls thinking, ‘Why are we not talking about this?’ “Sexual rights are not considered as rights. ‘Creating an issue out of a non-issue’ was the approach people took when the subject was raised. In the feminist movement, to bring in issues of disability was a challenge. But much has changed since then.” Understanding that sexuality is a spectrum and violence is a substantial part of sexuality, Nidhi observes that for people the only way sexuality work is legitimised is through violence, because we as a society still have a protection and control based approach rather than a rights based approach towards people with disabilities.

And so, Nidhi attempts to cover a range of issues that fall within the umbrella of sexuality rather than only menstruation, abuse, violence or hygiene management, or any such single piece of the

whole discourse, in the trainings she conducts. She emphasises the concept of sexual rights of disabled people while acknowledging that mindsets are hard to change (it is hard to counter the impact of a disabled woman being repeatedly told, “You are not good”). Nidhi speaks of experiences such as from Point of View’s sexuality and disability trainings<sup>258</sup> in which men with disabilities begin to respond with an increased acceptance and understanding of the concept of women with disabilities also having feelings and desires. Or when women at workshops initially refuse to speak of ‘these’ things but end up engaging with issues and reflecting on the change they want. “Many workshops have brought out positive indicators where participants have begun recognizing individual identity, are reflecting more on self-hood, and considering the concepts of choices and consent.” Nidhi through the sexuality and disability programme that she heads at Point of View has also begun training grassroots activists and trainers on disability, gender, sexuality and violence, as well as engaging with special educators to equip them on training their students with disabilities.

Sameera Shamim suggests that sexuality education could also be part of non-formal education at an institutional level where people with disabilities come together to learn vocational skills or life skills, as a lot of people with disabilities are a part of such institutional set ups. Various parents’ groups could have specific interactions and discussions on these issues in an open manner to share their experiences to help a wider group of people grappling with similar issues and concerns.

Also, 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>259</sup> Though the guidelines were developed for HIV and AIDS programmes they

258 POINT OF VIEW. Workshops – Sexuality and Disability. Retrieved from <http://workshop.sexualityanddisability.org/>

259 GROCE N. E., TRASI R. and YOUSAFZAI A. 2008. Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts. The World Bank. Retrieved from [https://www.ucl.ac.uk/lc-ccr/downloads/hivguidelines/HIV\\_Guidelines\\_on\\_Disability\\_-\\_World\\_Bank\\_-\\_ENGLIS.pdf](https://www.ucl.ac.uk/lc-ccr/downloads/hivguidelines/HIV_Guidelines_on_Disability_-_World_Bank_-_ENGLIS.pdf)

can be adapted to other programmes.

260 TARSHI. 2017. Internal documentation and reports.

Dipika Srivastava from TARSHI reports her experience as a participant at a workshop conducted by Point of View in April 2017.<sup>260</sup> The aim of the workshop was to share the process of organizing sexuality and disability workshops, making sexuality workshops accessible and nuanced across disabilities, conducting trainings with disabled women from diverse backgrounds and challenges that range from gate-keeping to cultural/ linguistic barriers. Dipika conducted a session on sexuality at this workshop where she highlighted the importance of talking about sexuality not just in terms of risk, violence and abuse, but also in terms of choice and pleasure. Amongst the key takeaways for Dipika, were a set of points to keep in mind while conducting workshops with people with disabilities. These include:

- To be careful using PowerPoint presentations, especially when there are people with visual impairment present
- Be willing to compromise. One of the participants said they were getting a lot of resistance when they wanted to speak about sexuality education, so they changed the name to Body Literacy. They now use the same content with a new name and no resistance.
- Everyone will not understand sexuality is not equal to sex, so we may need to break it down for them to understand what sexuality education includes and that it is not just about sex.
- Safety trainings can also provide the opportunity to talk about values, self-confidence etc.
- It is important to maintain relationships and keep meeting organisations, sometimes even without an agenda.

Workshops such as these are crucial forums for pooling experiences and knowledge amongst professionals who bring together diverse sets of expertise. They become resources for the training of trainers, a continuous process, necessary for sustaining work in the field,

for advocacy and for expanding the scope of outcomes and impacts from existing programmes.

## Accessible Information and Services

Often one of the factors preventing people with disabilities enjoying the same facilities and opportunities as others is the lack of accessibility. With a little bit of tweaking, this can be overcome.

The CREA report summarises suggestions from participants in the needs assessment study, “It was suggested that audio-visual material would be helpful for certain disabilities, sign language would be required for other groups. Many suggested using pictorial representations, music and tactile material. Accessible travel to training venue, accessible toilets, possible need for assistance for some participants would also need to be planned.”<sup>261</sup>

Here’s an inspiring example of what Abha Khetarpal has done. She has authored the book *Going with the Flow* on menstrual management and hygiene for women with disabilities. In her own words, “The management part of the book includes how menstruation can increase difficulties for women with different kinds of disabilities. It contains information about various absorbent materials that can be used and how to use them, when to change them, how to keep clean, what kind of food to eat and what kind of exercises can be done by girls with disabilities during the time of periods. It also contains tips for mothers, caregivers and even doctors. The book, in its various chapters uses pictorial presentations so that girls who are visual learners may understand the matter easily. The e-book version of the book is accessible for girls with visual impairment. I have written it in Hindi also as I want more and more girls and women to benefit from reading this book.”<sup>262</sup> Abha is also planning to make an audio-version of the book available. Accessible knowledge products such as this fill some part of the huge gap in SRHR education, information and services.

<sup>261</sup> CREA, ANJALI MENTAL HEALTH RIGHTS ORGANISATION, POINT OF VIEW, EQUALS CENTRE FOR PROMOTION OF SOCIAL JUSTICE and SRUTI DISABILITY RIGHTS CENTRE *Needs Assessment Report- Addressing Disability and Sexuality Rights, Closing the Gap – Building Institutional Capacity to Address Sexuality and Disability. (2016) (Unpublished Draft) .*

<sup>262</sup> FEMINISTS INDIA. 2015. *Going with the flow: A handbook on menstrual management & hygiene for women with disabilities.* Retrieved from <http://feministsindia.com/tag/abha-khetarpal/>

263 CHOWDHURY, S. (2015. August 7). Abha's app makes them cross hurdles. *Gadgets Now*. Retrieved from <http://www.gadgetsnow.com/tech-news/Abhas-app-makes-them-cross-hurdles/articleshow/48384615.cms>

264 CROSS THE HURDLES. E Learning Course. Retrieved from <http://crossthehurdles.org/etutoring/>

265 DAISY: Groundbreaking Technology for the Indian Sector. Available at <http://www.ngopulse.org/press-release/daisy-ground-breaking-technology-disability-sector> and LEIBS, A. 2014. DAISY Books Are Free, Downloadable Digital Audio Books. ThoughtCo. Retrieved from <https://www.thoughtco.com/daisy-books-free-digital-audio-books-198798>

266 TARSHI. 2010. *Sexuality and Disability*. Available at <https://www.bookshare.org/browse/book/229462?returnPath=L3NIYXJjaD9tb2R1bGV0YW1lPXB1YmxpYyZrZXl3b3JkPXRhcnoaQ%3D%3D>

267 FREEDOMSCIENTIFIC. (2015. March 15). *JAWS for Windows 20th Anniversary Video*. [Video file.] Retrieved from <https://www.youtube.com/watch?v=oDYjkF59jeo> and Freedom Scientific. 2017. The World's Most Popular Windows Screen Reader. Retrieved from <http://www.freedomscientific.com/Products/Blindness/JAWS>

268 BARRIER BREAK. Retrieved from <http://www.barrierbreak.com/>

Abha also designed the Cross the Hurdles mobile app that gives the user access to a variety of information that may be needed by a person with a disability, including such content as hospital and blood bank listings, where to get a disability certificate or an invalid carriage driving license (meant for a person with a disability to drive a vehicle that comes under the category termed 'invalid carriage') and a variety of other content. As described in a media article, the app covers education, health, employment, accessibility, legal guidance, transport facilities, assistive devices, sports, government and social schemes, offers career guidance, and provides links to job portals and information on financial assistance.<sup>263</sup> The app can also help locate a 24-hour pharmacy or a blood bank in a city. Cross the Hurdles also runs an online course making education from Class 5 to 10 accessible for students with disabilities.<sup>264</sup>

With new digital technology being developed across the world, many 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 synchronisation technology standard that allows people with diverse disabilities to access reading material.<sup>265</sup> Some of TARSHI's publications including the 2010 version of this working paper<sup>266</sup> are also available in this format on the bookshare.org website. In addition, the JAWS (Job Access With Speech) screen reading software is also being used widely in various institutions for the visually impaired in India. JAWS for Windows celebrated its 20<sup>th</sup> anniversary in 2015, where a video compilation presented tributes from users around the world.<sup>267</sup> Assistive digital technology has the immense potential to create an environment that is supportive of both the independence and the participation of persons with disabilities.

BarrierBreak<sup>268</sup> provides assistive technologies and accessibility solutions for reducing the experience of disability across a variety of circumstances. They are a pioneering social enterprise in this field in India. Shilpi Kapoor who started BarrierBreak, said in an interview:

BarrierBreak runs India's assistive technology and accessibility exhibition and conference called Techshare India where we help policy makers understand what is required in digital accessibility in India. In 2011, we have also created a portal called signntalk.org, which is a free sign language interpreter. We also created a Windows mobile app called Fun with Money for autistic children. This will help them understand the concept of money, how much money they have with them and how to transact money for buying things.<sup>269</sup>

She adds, "In a country where one can't change anything easily – be it healthcare or local transport, relying on technology which is ever-changing is only natural. BarrierBreak was founded on three basic principles – technology, hiring disabled (75 per cent of BarrierBreak's employees are disabled), as a fair organisation shouldn't believe in exclusion of any kind, and a for-profit model."<sup>270</sup> Such an approach to technology and the availability of resources such as these can be used to make information and resources related to SRHR available for people with disabilities in accessible formats.

Media is reporting on the technological innovations that are improving accessibility and creating a supportive environment for people with different kinds of impairments, particularly related to vision, speech and hearing. One such media article that appeared in 2017 reports on companies and innovators, gadgets, assistive devices and apps. These include the Eye-D app that uses the camera of a smartphone to guide a user with a visual impairment, Lechal shoes that are GPS enabled smart shoes that help with navigation, Blee watch for the hearing impaired and iGest that is an app that works with gestures thus providing tech support to a person with a speech impairment. As quoted in the article, Gaurav Mittal the co-founder of Eye-D, says, "Observing the world as a person who cannot see is hard. And they are slow to share deeply with us. What makes them laugh, what makes them cry, we need to know this to truly design a product that will help."<sup>271</sup>

According to the WHO-UNFPA Guidance Note 'accessibility' also

269 FRANCHISEINDIA.COM 2013. Breaking the Disability Barrier. Retrieved from <http://www.franchiseindia.com/entrepreneur/interview/emerging/techpreneur/Breaking-the-Disability-Barrier-202/>

270 VITTA, S. (2016. February 18). How Shilpi Kapoor is making accessibility a new normal through technology. *Your Story*. Retrieved from <https://yourstory.com/2016/02/shilpi-kapoor/>

271 UMACHANDRANI, S. (2017. November 7). How tech is making life easier for differently-abled. *The Times of India*. Retrieved from <https://timesofindia.indiatimes.com/india/how-tech-is-making-life-easier-for-differently-abled/articleshow/61538902.cms>

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. Many persons with disabilities in both industrialised 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 and violence are common. SRH professionals may need to address these populations specifically to ensure that they receive appropriate services.<sup>272</sup>

272 WORLD HEALTH ORGANISATION and UNFPA.2009. Promoting Sexual and Reproductive Health for People with Disabilities.

It is important to make information available in different formats (large print, audio versions for example) and at places that are accessible to people with disabilities. Existing services like helplines, counselling centres and other services if sensitised to the requirements of people with disabilities, can without much additional cost include disability issues in their programmes.

## 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. Merry Baruah from Action for Autism, 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 for a few instances they have to learn that self-gratification is a better option or probably the only option.” This speaks of the desolation that many people with disabilities face.

Rajendra Maurya wrote a book to challenge these barriers that Merry speaks about. Rajendra is married to Abha Khetarpal of Cross the Hurdles.

In 2017 he published the book *Defying Deviance: Sexuality and Disability* both as an e-book and in hard copy. The book is visualised as a guide for people who live with disability pain, illness or chronic conditions. In the preface, Rajendra says:

One fine day while I was sitting and thinking about the sexual lives of persons with disability, I realized that the sexual lives of disabled people is not same as non disabled people and it's not their disability that becomes a hurdle in expression of their sexuality but it is the mindset of the people around them who discriminate and segregate disabled from others in this matter.<sup>273</sup>

273 MAURYA, R. 2017. *Defying Deviance: Sexuality and Disability*. Cross the Hurdles. New Delhi.

He has referred often in the book to personal experiences and the relationship shared between him and Abha, clearly speaking from the perspective of lived experience and connecting readers to the realities of disability and sexuality across questions of identity as well. As Rajendra writes in the book:

The simple lack of acknowledgment of a right to sexuality emerges again and again in multiple different ways for persons with disabilities. For disabled women who express that their desire is directed towards other women, this right is even further limited, for those with mental health diagnoses or psychosocial disabilities, any evidence of same-sex desire is considered as a further sign of illness.

Communication emerging from such a space of personal knowledge sharing, human rights, advocacy and self-advocacy carries great weight and value in the movement to initiate increasingly mainstream discourse on these issues, as well as to create an enabling environment that fosters understanding and sensitivity.

Lakshmi Ravikanth of The Banyan says “Conversations on sexuality, sexual needs often emerge naturally as part of the process of recovery, where our women express wellness and desires to form intimate relationships. Radha (name changed) is asymptomatic, has a speech impairment, and attends computer classes. She communicated to a



274 Lakshmi Ravikanth. 2017.  
Personal communication.

social worker in the transit care home, of a mutual attraction that was forged with another man in class. They consider themselves as a couple and meet often in other places (beach, tea shops). She sought information on safe sex, while we also made her aware of various nuances of consent, and mutual satisfaction.”<sup>274</sup> These attitudes and approaches that are respectful of the right of persons with disabilities to information and education on sexuality are of the utmost importance. Lakshmi goes on to share, “Sexuality education typically warrants that our women need to know the difference between consent and abuse and be willing to share and report. Sexuality education affirms it’s ok to have desires for the same sex or to be bi-sexual. Aspects of contraception and sexual hygiene are well discussed. One of the women who is in her 30s lost both her husbands in a short span. She is daunted by marriage and desires sexual contact, which she felt that only marriage can provide. In her case masturbation was discussed, and a video on it was shown. She secretly called the counsellor and thanked her, as she feels she finds relief in this practice. Another woman likes the foreplay with her partner, but has worries about penetrative sex. It was discovered that she has a condition called vaginismus, and is being treated for it, while simultaneously being educated on ways to enjoy sex without pain.”

It is refreshing to note that there are organisations and individuals affirming the sexual rights of people with disabilities. And there are many more who are inquiring about how best this can be done. Pramada Menon asks, “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?”

These are questions that many people with disabilities, their parents,

care providers and professionals working in the field are already grappling with. 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. Incidentally, anecdotal evidence suggests that women in prostitution are welcoming of clients with disabilities, and yes, sex toys are available.

In a developing country like India where poverty is a reality for the majority of the population, we need to find workable propositions. 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. Anecdotal evidence suggests that some parents of people with disabilities are thinking out of the box despite being constrained by unfortunate realities that limit their options while trying to find a spouse for their disabled daughter or son. So, they propose to share their care on a rotational basis, with the couple with disabilities living for six months with the woman's family and moving to the man's family for the next six months. This gives 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. These are creative solutions that people are finding.

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 has been conducting 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.

Nidhi Goyal feels that there are two sides to creating special spaces for people with disabilities to meet each other for dating romance or marriage, “It’s a very problematic arrangement – reducing, categorizing, ghettoizing – your worth as a human being is reduced. But some people are happy with this arrangement, because they feel so discriminated against in larger society, so diminished in that space, that they feel they would rather find a partner in a space that treats them equally.”

The landscape of interaction and engagement for people has changed drastically in the last several years owing to the advent of new social media. However, here too there are in-built barriers that creep in from attitudinal barriers in the real world. Speaking of online dating websites, Nidhi Goyal explains that there are filters to include others’ choices, meaning that in the search fields a person with a disability gets screened out and does not show up in search results. Therefore access to people is limited to those with open mindsets, just as in the offline space. In the dating scenario, e-dating is not that popular, she says. Women think of safety first and this is even more of a consideration for women with disabilities. Also, these apps are not made according to accessibility guidelines. Describing her own experience testing the dating app ‘Truly Madly’ Nidhi says she first tried the app with the help of a friend. The app provides two buttons, ‘Yes’ and ‘No’ when you see a profile. Nidhi returned to the app independently a few days later, but had forgotten which button was which and was unable to use the app because of her visual impairment. “It is not just one app, but many apps which are made to make social and dating lives better are inaccessible (not made as per accessibility guidelines) thus mimicking the offline inaccessibilities in online spaces. The prejudiced assumptions here are very evident: One, the dating and socializing apps are not for

people with disabilities – they are asexual, undesirable, definitely invisible or why should they date when they have so much more going on. Two, their privacy in this very private aspect of life also doesn't matter because they are disabled – so they should take assistance and find their way.” Also, she says, according to research that the sexuality and disability programme of Point of View is doing, it is more difficult to find women with disabilities who are using dating apps, as opposed to finding men with disabilities who are using dating apps.

Unlike the app that Nidhi tried, Inclov describes itself as “the world’s first matchmaking app focusing on people with disability, and with health disorders to find love”.<sup>275</sup> The app is accessible to persons across diverse impairments including visual impairment, retina disorder, cerebral palsy and colour blindness, as well as for persons without disabilities. It has various security measures and verification processes to keep things safe for users. Kalyani Khona, co-founder, says in an article, “We realised that people across the globe have no inclusive matchmaking platform like Inclov, which is made accessible to every user irrespective of their disability or age”.<sup>276</sup> As mentioned on their website, Inclove also organises offline opportunities for meeting, an initiative called Social Spaces, “Inclov’s offline meetup platform where we aim to bring people with and without disability to come and meet in-person.”

While such technological advances and uses are changing the situation and the opportunities for inclusion for some people, common spaces for recreation and interaction in the real, as opposed to the virtual world remain an essential requirement for the overall wellbeing of an individual, as well as from the perspective of sexuality.

People with disabilities, like anyone else, have the right to a social life, to leisure, to recreation, to meet others, and to form fleeting or lasting relationships. Organisations can develop opportunities and spaces for regular meetings, festivals, cultural and art events that foster an environment where persons with and persons without

275 INCLOV. Retrieved from <http://www.inclov.com/>

276 BANERJEE, R. (2016. March 16). With Her App, One Woman Is Trying To Make Finding Love Easier For The Differently-Abled. Youth Ki Awaaz. Retrieved from <https://www.youthkiawaaz.com/2016/03/inclov-dating-app-for-the-disabled/>

disabilities can meet and interact socially. The government has an important role to play here by providing disabled-friendly transport and making commuting accessible for the success of these programmes.

## Research

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 still 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 in mainstream research, whether on sexuality or otherwise, almost implying that people with disabilities do not count. This is particularly true of children with disabilities. Amongst the key barriers to designing and conducting research is access to people, especially to children and young people with disabilities.

In 2006, Nisha, a women's rights advocate wrote:

Considering that so many negative perceptions about the sexuality of disabled persons go unchallenged, there is a need to carry out empirical work to reclaim the sexual experiences of disabled people. This must be done for three reasons: to substantiate the fact that disabled people are indeed perceived as asexual and face multiple barriers to their sexuality, and to make the non-disabled world accept and value disabled persons' sexuality; to bring sexuality onto the disability movement's agenda; to validate the experiences of disabled persons. Positive cultural representations of the sexuality of disabled persons are important not only to change public perceptions but also to impact on disabled persons' access to sexually meaningful relationships.<sup>277</sup>

<sup>277</sup> NISHA. 2006. Regulation of disabled women's sexuality.

The lack of research or a rights based thought process and/or inadequate research skills, 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. In this 2012 article based on a study, *Disability and Rehabilitation Services in India: Issues and Challenges*, which primarily uses a public health and medical, rehabilitational approach to consider issues of disability, the researchers have, among other recommendations, said this:

Increase public awareness and understanding of disability. Governments, voluntary organisations, and professional associations should consider running social marketing campaigns that change attitudes on stigmatized issues such as HIV, mental illness, and leprosy. Involving the media is vital to the success of these campaigns and to ensuring the dissemination of positive stories about persons with disabilities and their families.<sup>278</sup>

A small effort is made to view disability keeping social barriers in mind. So the authors do say:

Research is essential for increasing public understanding about disability issues, informing disability policy and programmes, and efficiently allocating resources. Some of the important areas of research can be quality of life and well-being of people with disabilities; barriers to mainstream and specific services, and what works in overcoming them in different contexts; accessibility and universal design programmes appropriate for low-income settings.

However, a rights-based approach and style of communication is missing and there is certainly no mention of personal relationships or sexuality; the general approach remains mired somewhere between the old medical model, including use of the word 'handicap', combined with a tentative move towards articulations and ideas that try to reflect participation, inclusion and social elements.

278 KUMAR, S.G. ROY, G. KAR, S.S. (2012) Disability and Rehabilitation Services in India: Issues and Challenges. *J Family Med Prim Care*. 2012 Jan-Jun; 1(1): 69-73. Abstract Retrieved from <http://www.jfmprc.com/article.asp?issn=2249-4863;year=2012;volume=1;issue=1;spage=69;epage=73;aulast=Kumar>

The fact remains that research on disability in India is crucial for effective policy formulation, strategic designing and planning for advocacy and also in planning intervention programmes or services for people with disabilities in India. This requires training of researchers from a disability rights lens and where possible, inducting researchers who are living with disabilities themselves.

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). Global and local studies, such as have been undertaken by CBM, CREA, Foundation for Social Transformation, Human Rights Watch, Inclusion International, Kevan Moll, Renu Addlakha, Project Signpost, and WOHTRAC, among others, have provided significant inputs for this paper.

More research studies, both quantitative and qualitative, continue to be a priority. These must 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. Janet Price offers some suggestions for possible research ideas saying, “Research in India needs to begin with a challenge to Northern/minority world based concepts of disability. The ideas for example, of sexuality as an individual issue, in isolation from family and community forces; of health care as an issue the woman decides about personally rather than in consultation or determined by the men of the household; recognition of the differences of stigma, felt strongly within the minority world, and shame, experienced by many disabled people in the majority world; these and other issues need to assist in reformulation of concepts for disabled people from India.”

Individuals and organisations focusing their work on sexuality are indeed fine-tuning the approach to research projects, looking at the unique requirements and circumstances of specific segments of

people. Kiran, who shared his story of standing at the intersections of disability, sexuality and caste and class, is currently undertaking a Fellowship project funded by the Solidarity Foundation looking at the particular experiences and issues of female to male transgender persons. As he explains in an interview:

There are many organisations working on transgender issues, but many individuals are not able to come out as female-to-male transgender. There are barriers – how to disclose your identity, no place to meet, no access to support. There are barriers to finances. No access to psychosocial support. For the female-to-male name change there are ID card problems, job problems, shelter/tenancy issues. These basic problems.<sup>279</sup>

279 ALEYA, S. 2017. Interview with disability and sexuality rights activist Kiran.

The different connections between the variables that affect access to opportunities and even to basic services are deserving of study. As Kiran elaborates:

I was born as a female child, so all the documents were in the female name itself. Whenever I want to change those things I am always facing challenges. For the transfer of the pension scheme also, I struggled a lot. When I was in Telangana I used to get that pension, but after coming to Karnataka they were refusing to give the pension. Also my caste was ST (Scheduled Tribe) in Telangana but, in Karnataka, they give the caste certificate as SC. These things are very crucial.<sup>280</sup>

280 Ibid.

Also, 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



281 SEYMOUR, W and LUPTON, D. 2004. Holding the Line Online: Exploring Wired Relationships for People with Disabilities. *Disability and Society*, Vol.19, No. 4.

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>281</sup>

At the time of updating this paper, the literature review exercise was primarily conducted online and mostly yielded resources in the nature of short articles, blogs and news pieces. References to India-focused research or research investment on the subject of sexuality and disability were in the nature of the need for such, rather than actual such content. In conversations with self-advocates and individuals and organisations working on issues of disability and inclusion, sexuality as a critical theme enters the conversation often. There is still a significant degree of resistance amongst many people, care providers, families, individuals with disabilities and even resource persons such as teaching staff to focus on the subject, as has been reported in studies quoted in this paper and as is narrated by some of the resource persons who contributed their inputs to this paper. Yet, there is a greater visibility of the connection between sexuality and disability.

Looking ahead, 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.

## 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 to 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.

The WHO and UNFPA Guidance Note on promoting sexual and reproductive health for people with disabilities says that 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>282</sup> Implementation strategies for the new RPD Act 2016 that has been passed are of critical importance. This Act that replaces the PWD Act 1995, changes the understanding of disability per se and a broader approach is needed in order to be able to change mindsets and provide necessary services. The intense advocacy and engagement building by multiple individuals and organisations on the RPD Rules and aspects of the law critical to bringing about change are reflective of the efforts in pursuance of this. Still, more awareness about the sexual rights of people with disabilities is needed.

The Guidance Note recommends that 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 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.

As the WHO and 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

282 WORLD HEALTH ORGANISATION and UNFPA.2009. Promoting Sexual and Reproductive Health for People with Disabilities.

283 Ibid.

assurance that programmes will meet needs effectively.<sup>283</sup> If people with disabilities are a part of all planning processes, including those that formulate state policies, they will articulate their own needs in a manner that is relevant to them, take decisions and formulate plans on their own behalf.

As Janet Price suggests, “This is where feminists can play a crucial role. They have wide experience in the field of advocacy for sexuality and sexual and reproductive health and rights, and could work alongside disabled women to support them in identifying their priorities, strategizing for how to publicise and negotiate for them, and provide woman power to assist disabled women in following through on their advocacy plans to meet their dreams of sexual rights and justice.”

In fact, some of this is already happening. The increasing participation of people with disabilities at international gatherings is also bringing issues of disability to the forefront. It is encouraging to note that more spaces are opening up for this. Association for Women’s Rights in Development (AWID) is an international feminist organisation that brings together around 2000 women’s rights leaders, activists, funders and grassroots workers every three or four years in what has come to be called the AWID International Forum. More than 1800 feminists from more than a hundred countries across the globe participated in the 13<sup>th</sup> AWID International Forum in Brazil in 2016. Such platforms provide opportunities for amplifying voices from different parts of the world.

At the 2016 Forum, there was a strong presence of disability rights activists, in fact, the strongest so far. Representatives from CBM (an international organisation committed to improving the quality of life of people with disabilities in the poorest communities in the world) attended this Forum and interviewed disability rights activists from Nigeria and Madagascar. The narratives contained in these interviews, while drawing from the experiences within a particular country, mirror the experiences of women with disabilities in other countries as well. Irene Ojiugo, executive director of the Disability

Rights Advocacy Centre (DRAC) in Nigeria, says in the interview:

Women with disabilities still face many barriers – lack of access to sexual and reproductive health (including physical barriers, attitudes of health care providers etc). Women with disabilities also lack access to education and information, leading to self-esteem issues. Additionally, we are invisible when it comes to governance – women with disabilities tend to be relegated to the background all the time. We also face high levels of gender-based violence and still have no access to employment and livelihood opportunities.<sup>284</sup>

284 CBM. 2016. Disability and the women's agenda: we work to see change happen. Retrieved from <http://www.cbm.org/Disability-and-the-women-s-agenda-516299.php>

Razaka Ralphine, who is with the Ministry of Population, Social Protection and Gender Promotion in Madagascar as Director at Persons with Disabilities and the Elderly, says:

As a woman with a disability living in a developing country, I think there is still a lot to be done in terms of awareness and advocacy within the women's movement itself. I feel like they are not truly aware of the issues faced by women with disabilities, so we need to shed more light on that and get the conversation started.<sup>285</sup>

285 Ibid.

These are only two voices that we quote here. There were many more heard at the Forum.

Janet Price was also at the 2016 AWID International Forum and summed up her experience there by saying, "The largest number of disabled women, ever, attended the forum – over a hundred. Sexuality came up in a number of ways: in debates about reproduction, about pathologisation and normalisation, about including trans, disabled and intersex people. There was a session about our work around sexuality and disability. There was a discussion about the Coalition for Disability, Sexuality and Rights in Africa. There were Arts and Rights based disability workshops with Reshma Valliappan, Lizzie Klama and Grindl Dockery. Amongst other issues about women, their bodies and sense of themselves, questions about violence emerged. And best of all, there were lots of disabled women on the

dance floor, beautiful, sexy and dancing the night away!!! Many saying that it's rare to find a space where that is possible for them – whether using crutches, in wheelchairs, visually impaired, where we may take up space – and this venue provided that for us.”

Gatherings such as these serve not only as a space for advocacy and drawing strength from other social movements, they also serve to inform and educate people in positions of power and authority as well as grant-makers who can contribute important monetary and other resources. As a result of the disability rights activism at the Forum, here is what Serap Altinisik, Programme Director at the European Women's Lobby (EWL), a network of more than 2000 women's organisations across Europe, had to say:

The voices of women with disabilities were also a fundamental component at the forum. For example, they challenged the concept of what it means to be 'able'. And this was particularly prevalent in our EWL session regarding funding women's rights organisations. We had the opportunity to learn from activists on disabilities on how we can be more successful when we are mainstreaming diversity in our strategies within the funding landscape of women's rights organisations.<sup>286</sup>

286 ALTINISIK, A. (2016. October 11). Takeaways from the AWID Forum. Retrieved from <http://www.womenlobby.org/Takeaways-from-the-AWID-Forum>

## Disability Studies

The past 15-20 years have 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), Disability Studies as an interdisciplinary academic discipline was granted recognition by the Ministry of Human Resource Development (MHRD), 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.

287 NALSAR University of Law. Centre for Disability Studies. Retrieved from <http://www.disabilitystudiesnalsar.org/index.php>

288 IGNOU. National Centre for Disability Studies (NCDS). Retrieved from <http://www.ignou.ac.in/ignou/aboutignou/icc/ncds/introduction>

National Academy of Legal Studies and Research (NALSAR) University of Law<sup>287</sup>, the Indira Gandhi National Open University

(IGNOU)<sup>288</sup> and the Tata Institute of Social Sciences (TISS)<sup>289</sup> have academic programmes, including at the Master of Arts (M.A) level, in Disability Studies. Courses in disability studies are also offered at Alagappa University<sup>290</sup> and Guwahati University.<sup>291</sup> 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. At the time of finalising this Working Paper, the media reported<sup>292</sup> plans at Delhi University to start a Centre for Disability Studies.

The National University of Rehabilitation and Disability Studies Bill, 2016, is pending with the Department of Empowerment of Persons with Disabilities, of the Ministry of Social Justice and Empowerment (MSJE), Government of India. The stated purpose behind this proposed legislation is:

To establish and incorporate a University for Rehabilitation and Disability Studies for the purpose of ensuring proper and systematic instruction, teaching, training, and research in the matter of physical, mental and other form of disabilities of individuals, rehabilitation and allied sciences in the country and to have uniformity in various academic and rehabilitation programmes in the disability sector in the country and to provide for matters connected there with or incidental there to.<sup>293</sup>

The current status of this Bill is not known to us at the time of writing this paper. A desk review has yielded some references to it, including one at Punarbhava, the National Web Portal on Disabilities. Part of the descriptive text in this reference says, “The central government’s aim is to have a country with people with no disabilities and if at all there are such people, the government will provide necessary support and education for them and equip them with instruments, devices and other facilities to help them fully included in the mainstream.”<sup>294</sup>

One may perceive text such as that quoted above as reflecting

<sup>289</sup> TISS. Centre for Disability Studies and Action. Retrieved from <http://103.36.84.41:8012/live/Tiss/TopMenuBar/academic/centres-of-schools/centres-of-school-of-social-work/centre-for-disability-studies-and-action>

<sup>290</sup> ALAGAPPA UNIVERSITY. Department of Special Education and Rehabilitation Science. Retrieved from [http://alagappauniversity.ac.in/academic/department/about\\_us/37](http://alagappauniversity.ac.in/academic/department/about_us/37)

<sup>291</sup> GAUHATI UNIVERSITY. Disability studies. Retrieved from <http://www.gauhati.ac.in/arts-disabilities-studies.php>

<sup>292</sup> TNN. (2017. November 19). At convocation, Delhi University floats plan for disability studies. *Times of India*. Retrieved from <https://timesofindia.indiatimes.com/city/delhi/at-convocation-du-floats-plan-for-disability-studies/articleshow/61706746.cms>

<sup>293</sup> GOVERNMENT OF INDIA. The National University of Rehabilitation and Disability Studies Bill, 2016. Retrieved from <http://www.disabilityaffairs.gov.in/content/viewpage/the-national-university-of-rehabilitation-and-disability-studies-bill-2016-.php>

<sup>294</sup> REHABILITATION COUNCIL OF INDIA (RCI).Punarbhava. National Web portal on Disabilities. The National University of Rehabilitation and Disability Studies Bill, 2016. Retrieved from <http://lms.punarbhava.in/index.php/the-national-university-of-rehabilitation-and-disability-studies-bill-2016.html?date=2016-10-01>

a lack of considered approach in communication on disability, which needs to change, even as we discuss the subject of disability studies. An analysis of this piece of communication using the human rights lens throws up many problems with approach and articulation, as acceptance, respect, dignity, sensitivity and empowerment find no place in it. Besides which, the sense of 'othering' ensures that the gap widens between the entitled and the vulnerable and continues to reinforce the attitude that a person with a disability is somehow less, and of less value, than a person who does not have a disability. Both idea and articulation require constant monitoring of any communication, particularly when the source represents an official position.

# CONCLUSION

## Things are changing

As we come to the end of this working paper, certain points remain top of mind. Some conclusions may be drawn on the basis of these, for thought, discussion and programme planning.

To begin, it is clear that the connections between disability and sexuality are still not often identified or articulated and many disempowering and stigmatising myths exist, contributing to large scale human rights violations. These connections require investment into research and study, to build and strengthen the evidence base for advocacy and intervention programmes. Information on demographic, social, economic, health, and the general context of life and relationships of persons with disabilities is scarce. Information about existing sexuality and sexual and reproductive health related initiatives in the context of disability is even scarcer. The accessibility of this information is another crucial matter to consider as not being able to access existing information contributes to the further disenfranchisement of vulnerable populations.

In spite of this, there is a sense of change and movement as many new resources and investments have been made since 2010 by organisations, individuals and self-advocates focusing on sexuality and disability and the intersections with gender, caste, class, health status, economic and educational background, among other factors.

## New voices and new spaces are emerging

While sexuality is still largely considered taboo in India and many



parts of South Asia there are some new spaces and voices that are addressing sexuality concerns of persons with disabilities as well as efforts that expand advocacy and access to resources and information in India. At the regional and global level too, there are organisations and initiatives that bring focus on the sexual and reproductive health rights of persons with disabilities at international fora. It is important to make the connections across these efforts and build on shared knowledge across diverse experiences. For this, knowledge collection and information sharing through accessible information and outreach events is crucial.

India has its own particular context and diversity of mindset, political and socio-cultural. This requires deep levels of strategic study and thought for the purpose of bringing about any change. So while some national laws, international human rights documents and other consensus statements recognize that human rights embrace sexual rights India remains wary and distanced from these. Attitudes to sexuality education in schools are a huge barrier. Under these circumstances it becomes very difficult to speak of sexuality in the context of children with disabilities. It has also been noticed that where information on sexuality is provided to children or young people with disabilities, it is restricted 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. The 2017 report of the UN Special Rapporteur on the rights of persons with disabilities, affirms the importance of sexuality education and specifically identifies this as one of the key factors for implementing sexual and reproductive health and rights of girls and young women with disabilities.

According to the report:

States need to provide comprehensive and non-discriminatory sexuality education to girls and young women with disabilities, both within and outside school (see A/65/162, paras. 62 and 87). It should include information about self-esteem and healthy

relationships; sexual and reproductive health, contraception and sexually transmitted diseases; the prevention of sexual and other forms of exploitation, violence and abuse; stigma and prejudices against persons with disabilities; gender roles; and human rights. Indeed, sexuality education has been found to be effective in improving the sexual knowledge and skills of youth with disabilities, and in reducing sexual violence against them.<sup>295</sup>

Another issue is the lack of focus on appropriate communication methodology, effectively ignoring that different types of impairments impose different challenges to communication and understanding. Yet, despite these barriers a positive note emerges alongside – sexuality issues are being discussed in the disability sector as we have seen in the examples through this paper. Training resources, accessible information, disaggregated data collection and more platforms for experience sharing are essential. Training of persons with disabilities on SRHR from the perspective of becoming self-advocates, trainers and subject researchers, is another area that requires investment and resources.

### Changing mindsets across sectors and spaces remains a primary challenge

Further to issues of changing mindsets that contribute to rights violations and injustice, we can also conclude that more people need to be brought in to understand and participate in discussions on disability. Attitudes to disability impact issues of sexuality of persons with disabilities. The framework with which disability is approached has changed over time from a charity-based one to a rights-based one and now even more recently to a perspective of neurodiversity and disability justice. These are important advances because disability justice brings forward powerful new ways of perceiving bodies, understanding intersectionality and valuing people, and the neurodiversity perspective places acceptance and respect as tools for constructing an empowering and rights based approach to human diversity. We put forward the thought

295 UNITED NATIONS OHCHR. 2017. *Report of the Special Rapporteur on the rights of persons with disabilities*. Retrieved from <http://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/Reports.aspx>

that perhaps it is time for us in India to catch up with a changing conversation.

Between 2010 and 2018, the landscape of laws in the country has changed enormously. This brings its own set of challenges as new laws require implementation rules, guidelines, interpretations and strategies, and an understanding of the spirit behind the law and advocacy that helped change these laws. The RPD Act, 2016 is now in force.<sup>296</sup> Rules were notified for implementation of this Act in June 2017. There is criticism of both the process of drafting the Rules and the content. The NPRD suggestions to the Draft Rules addressed gender and sexuality issues and took into account the fact that issues of disability and sexuality emerge across laws protecting rights/ addressing rights violations and therefore implementation of laws must look to the connections between them as well. However, as mentioned earlier, these suggestions were not accepted.

296 GOVERNMENT OF INDIA. Rights of Persons with Disabilities Act, 2016. Retrieved from <http://www.disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf>

Similarly, there are intense debates and disagreements on the intent and provisions of the Mental Health Care Act, 2017, but it is important to highlight that for once non-discrimination on the grounds of sexual orientation has found a mention in a Bill passed by Parliament. This has significant implications for advocacy.

### **Differences exist and resources and services must cater to these differences**

When discussing disability and sexuality, one must be conscious that there are many different types of impairment and different degrees of disability may be experienced in different environments. There are also individuals who may experience more than one disability. The understanding and the mechanisms to approach specific challenges associated with specific disabilities need 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 and concerns from one another, and therefore there can be no single solution. Also, a narrow definition of disability implies that many people are excluded from surveys

and information gathering or service outreach exercises. There are also some groups of people with disabilities who are at particularly high risk of facing discrimination and sexual violence – for instance women with disabilities in conflict areas or during migration / forced migration – but not enough focus is given to them, rendering them and their experiences invisible.

### **Persons with disabilities have the right to exercise choice**

Societal attitudes which define persons with disability by their disability alone fail to acknowledge the person as a whole. They are perceived to be sexually undesirable and therefore incapable of being in sexual or in intimate relationships. This further leads to the belief that people with disabilities do not get sexually assaulted or abused as no one will desire them. It also results in a severe lack of resources and support for them. People with disabilities in India are often socialised to be dependent and this makes it hard for them to develop skills of thinking independently, and even harder to practice essential independence. Well-intentioned care providers and family members usually treat people with disabilities like children even when they are adults and capable of making their own decisions. Lack of privacy is a further barrier. 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. People need to meet other people to form relationships, but opportunities for socialising are limited for people with disabilities because of the inaccessibility of physical and virtual spaces. Sexuality is almost always associated with heterosexual marital relationships, making heterosexual dating relationships or same sex relationships impossible to think about. Compounding all this is the lack of access to information and services. But, as we see from the examples in this paper there are multiple growing efforts in India over the last several years by people with disabilities themselves, parents, teachers, other caregivers, disability rights activists, and others to affirm

the sexual rights of people with disabilities. They are doing this in a range of ways, including through sexuality education sessions, increasing supportive spaces, providing information and services, creating usable resource material, but above all, through believing that persons with disabilities are persons who have the right to exercise choice.

# 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

297 GOVERNMENT OF  
INDIA. Rights of Persons  
with Disabilities Act, 2016.  
Retrieved from [http://www.  
disabilityaffairs.gov.in/upload/  
uploadfiles/files/RPWD%20  
ACT%202016.pdf](http://www.disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf)

As listed in the RPD Act, the 21 disabilities now covered are<sup>297</sup>:-

### 1. Physical disability.—

A. Locomotor disability (a person’s inability to execute distinctive activities associated with movement of self and objects resulting from affliction of musculoskeletal or nervous system or both), including—

- (a) “leprosy cured person” means a person who has been cured of leprosy but is suffering from—
  - (i) loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eye-lid but with no manifest deformity;
  - (ii) manifest deformity and paresis but having sufficient mobility in their hands and feet to enable them to engage in normal economic activity;
  - (iii) extreme physical deformity as well as advanced age which prevents him/her from undertaking any gainful occupation, and the expression “leprosy cured” shall construed accordingly;
- (b) “cerebral palsy” means a Group of non-progressive neurological condition affecting body movements and muscle coordination, caused by damage to one or more specific areas of the brain, usually occurring before, during or shortly after birth;
- (c) “dwarfism” means a medical or genetic condition resulting in an adult height of 4 feet 10 inches (147 centimeters) or less;
- (d) “muscular dystrophy” means a group of hereditary genetic muscle disease that weakens the muscles that move the human body and persons with multiple dystrophy have incorrect and missing information in their genes, which prevents them from making

the proteins they need for healthy muscles. It is characterised by progressive skeletal muscle weakness, defects in muscle proteins, and the death of muscle cells and tissue;

- (e) “acid attack victims” means a person disfigured due to violent assaults by throwing of acid or similar corrosive substance.

B. Visual impairment—

- (a) “blindness” means a condition where a person has any of the following conditions, after best correction—
  - (i) total absence of sight; or
  - (ii) visual acuity less than 3/60 or less than 10/200 (Snellen) in the better eye with best possible correction; or
  - (iii) limitation of the field of vision subtending an angle of less than 10 degree.
- (b) “low-vision” means a condition where a person has any of the following conditions, namely:—
  - (i) visual acuity not exceeding 6/18 or less than 20/60 upto 3/60 or upto 10/200 (Snellen) in the better eye with best possible corrections; or
  - (ii) limitation of the field of vision subtending an angle of less than 40 degree up to 10 degree.

C. Hearing impairment—

- (a) “deaf” means persons having 70 DB hearing loss in speech frequencies in both ears;
- (b) “hard of hearing” means person having 60DB to 70 DB hearing loss in speech frequencies in both ears;

- D. “Speech and language disability” means a permanent disability arising out of conditions such as laryngectomy or aphasia affecting one or more components of speech and language due to organic or neurological causes.

2. Intellectual disability, a condition characterised by significant

limitation both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behaviour which covers a range of every day, social and practical skills, including—

- (a) “specific learning disabilities” means a heterogeneous group of conditions wherein there is a deficit in processing language, spoken or written, that may manifest itself as a difficulty to comprehend, speak, read, write, spell, or to do mathematical calculations and includes such conditions as perceptual disabilities, dyslexia, dysgraphia, dyscalculia, dyspraxia and developmental aphasia;
- (b) “autism spectrum disorder” means a neuro-developmental condition typically appearing in the first three years of life that significantly affects a person’s ability to communicate, understand relationships and relate to others, and is frequently associated with unusual or stereotypical rituals or behaviours.

3. Mental behaviour—

“mental illness” means a substantial disorder of thinking, mood, perception, orientation or memory that grossly impairs judgment, behaviour, capacity to recognise reality or ability to meet the ordinary demands of life, but does not include retardation which is a condition of arrested or incomplete development of mind of a person, specially characterised by sub normality of intelligence.

4. Disability caused due to—

(a) chronic neurological conditions, such as—

- (i) “multiple sclerosis” means an inflammatory, nervous system disease in which the myelin sheaths around the axons of nerve cells of the brain and spinal cord are damaged, leading to demyelination and affecting the ability of nerve cells in the brain and spinal cord to communicate with each other;
- (ii) “Parkinson’s disease” means a progressive disease

of the nervous system marked by tremor, muscular rigidity, and slow, imprecise movement, chiefly affecting middle-aged and elderly people associated with degeneration of the basal ganglia of the brain and a deficiency of the neurotransmitter dopamine.

(b) Blood disorder—

- (i) “haemophilia” means an inheritable disease, usually affecting only male but transmitted by women to their male children, characterised by loss or impairment of the normal clotting ability of blood so that a minor wound may result in fatal bleeding;
- (ii) “thalassemia” means a group of inherited disorders characterised by reduced or absent amounts of haemoglobin.
- (iii) “sickle cell disease” means a hemolytic disorder characterised by chronic anemia, painful events, and various complications due to associated tissue and organ damage; “hemolytic” refers to the destruction of the cell membrane of red blood cells resulting in the release of hemoglobin.

- 5. Multiple Disabilities (more than one of the above specified disabilities) including deaf blindness which means a condition in which a person may have combination of hearing and visual impairments causing severe communication, developmental, and educational problems.
- 6. Any other category as may be notified by the Central Government.

## APPENDIX III

Extract from NPRD suggestions of April 2017 to the Draft Rules to the Rights of Persons with Disabilities Act, 2016:

‘Section 7 of RPD Act– Protection from Abuse, Violence and Exploitation

Add the following rules:

1. Under this section the term ‘Abuse’ shall be understood as:

Any act or series of acts including physical force on the body of the person with disability or insulting, ridiculing or humiliating or any conduct of a sexual nature that violates the dignity of the victim, or depriving with financial and economic resources or denial of food and fluids or depriving or denying support which the person with disability had demanded or which could be reasonably understood to have been demanded, with the intention to cause physical, emotional or mental injury and includes regular attempts at doing such acts.

2. Under this section the term ‘Violence’ shall be understood as:

Any act of commission or omission whether individually, collectively or by state sanction, whether the sanction is tacit or explicit, that results in or is likely to result in physical, sexual, emotional and/or psychological harm or suffering including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.

...

4. Under section 7(1), add:

The appropriate government shall ensure the training of protection officers under the Protection of Women from Domestic Violence Act, 2005 and women helpline operators on disability related issues.

5. Under section 7(1), add:

The appropriate government shall ensure the training of officers under the Protection of Children from Sexual Offences Act and all the professionals specified under the POCSO rules on disability related issues.

...

#### Section 16 –Education

Add the following rules:

...

2. It shall be mandatory for all schools to provide comprehensive sexuality education, which shall be made available in accessible formats for all children with disabilities by professionally trained personnel. In-case of children with intellectual disabilities, training on sexuality education shall also be imparted to their family members/care-givers.

...

#### Under Section 24 of RPD Act – Social Security

Add the following rules:

...

7. The appropriate government shall ensure that policies are framed for providing support to women with disabilities for upbringing their children at least till the child attains five years of age.

...

Under sub-section 25(2)(k) add:

...

11. The appropriate government shall take measures to ensure that all medical personnel including doctors, nurses and para-medical staff are sensitized and trained on the rights and issues of sexual and reproductive health of people with disabilities especially women with disabilities.’<sup>298</sup>

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## APPENDIX IV

Apart from the laws and policies already discussed in the paper, here are some other laws and policies to be read as they might apply to issues of disability and sexuality:

- The Sexual Harassment of Women at Workplace (Prevention, Prohibition and Redressal) Act, 2013<sup>299</sup>
- Section 377 of The Indian Penal Code, 1860<sup>300</sup>
- Immoral Traffic Prevention Act, 1956<sup>301</sup>
- Medical Termination of Pregnancy (MTP) Act 1971 and the MTP (Amendment) Act, 2002<sup>302</sup>
- The Protection of Women From Domestic Violence Act 2005<sup>303</sup>
- National Population Policy 2000<sup>304</sup>
- Draft National Health Policy 2015<sup>305</sup>
- National Health Policy 2002<sup>306</sup>
- National Youth Policy 2014<sup>307</sup>
- National AIDS Control Programme Phase IV<sup>308</sup>

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## ABOUT TARSHI

TARSHI is an NGO based in New Delhi, India, working on sexuality and Sexual and Reproductive Health and Rights (SRHR) since 1996.

TARSHI believes that all people have the right to sexual wellbeing and to a self-affirming and enjoyable sexuality. TARSHI supports and enables people's control and agency over their sexual and reproductive health and wellbeing from an affirmative perspective, focusing not only on violence prevention, reducing unwanted pregnancies or infections, but also on pleasure and individual rights to self-identity, safe and enjoyable sexual and reproductive health. TARSHI strives to be as inclusive as possible and work for the sexual and reproductive rights of all people, irrespective of their gender or sexual identities, disability, class or caste locations.

TARSHI conducts trainings and online courses on sexuality and SRHR, develops publications, runs a bi-monthly eMagazine In Plainspeak and a 24X7 bilingual infoline, and actively disseminates information on SRHR on social media. For more information, visit [www.tarshi.net](http://www.tarshi.net).



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