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ARTIVISM AND THE LAST AVANT GARDE¹: A Route to Sexuality, Embodiment, and Disability Justice

Introduction. Anne Finger² said some years ago that for disabled people, sexuality can be part of our deepest oppression and deepest pain, yet it can also be one of our greatest pleasures. However, since the start of the struggle for disability rights, sexuality has not been viewed as a priority, receiving limited active recognition. It has continually been displaced in campaigns by the urgency of demands for education, jobs, homes, and healthcare. Yet the idea of sexuality as a luxury is gradually beginning to fade amongst disability activists. There is a recognition that the desire that most of us, disabled or not, feel for closeness, companionship, touch, an active sense of our sexual selves, and yes, sex itself, is held very deeply—a necessary and ever-changing element of those things that make us the persons we are. But finding ways of addressing these differing aspects of sexuality is a challenge. One of the disability-led organisations that play a vital role in opening up some of the hidden spaces around sexuality is DadaFest, a disability- and deaf-led arts organisation and festival space.

There is a recognition that the desire that most of us, disabled or not, feel for closeness, companionship, touch, an active sense of our sexual selves, and yes, sex itself, is held very deeply—a necessary and ever-changing element of those things that make us the persons we are.

DaDaFest: Encountering Sexuality through Disability and Deaf Arts.

Started in Liverpool over 30 years ago, DaDaFest (the Disability and Deaf Arts Festival: DDF)³ acts as a channel for developing and sharing the ideas of disability artists—art that serves as a force to claim justice⁴ and rights for disabled people. DaDaFest advocates for disabled artists⁵ to develop professional and artistic skills, and cuts through the discrimination they face within both the art world and amongst the broader public. Producing a wide range of visual and performance arts and working through local and global connections, one of DaDaFest's aims is to challenge assumptions about disability. They disrupt ideas of non-normative bodies, minds and emotions, demonstrating the depth of skills and ideas amongst those whose bodies are formed differently to

the symmetrically balanced norm, whose thoughts and emotions follow uncommon pathways.

Furthermore, DaDaFest is increasingly recognising the importance of engaging with intersectional aspects of identities. Gender, sexuality, class, and race issues are crucial to understanding how subtleties of discrimination arise around disability. Additionally, all disabled people have to confront a bewildering range of misapprehensions about their sexual actions, identities and desires. Reflecting the many potential ways of living as disabled, the work DaDaFest produces is thus often edgy, challenging heteronormative disability stereotypes, questioning fixed ideas of the “body beautiful,” and undermining stigma and prejudice about beliefs of disabled people's non-sexual lives.



Photo Credit: DaDaFest

Bodies Reveal. The painter **Tanya Raabe** has created several works shown at DaDaFest which explore new ways of seeing bodies, each with its own individual, lived-in marks of years passed. Tanya's paint reveals what was previously secret, enabling us to glimpse their stories. Tanya unwraps, in a life drawing class called *The Nude: ReDressed*,⁶ a reworking of the *Three Graces*. We are offered new perspectives, non-verbal ways of engaging with the curves of these non-normative bodies, the shapes exposed and not concealed, as her painterly skills uncover the joy and the pain experienced.

The societies in which so many of us live are deeply intolerant of difference. Physical and psychosocial difference leads many to feel uncomfortable; anxiety about the unfamiliar is used as an excuse for the verbal, physical, and sexual violence thrown at disabled people. Why do so many people find difference so disruptive that they respond with threats and hate? Many people manage their lives to ensure limited exposure to these bodies that can so disturb—the bodies Tanya paints of differing shapes, with twists and swellings, curves and absences in unexpected, unusual places. Finding words to describe them that aren't value-based—that don't speak of "deformity," of "cripple"—is difficult. *R:Evolve*⁷ comprises three squares, each side painted with a section of a different individual, mounted with heads atop torsos atop lower limbs. When in alignment, it shows four full-length portraits of disabled people, divided by the squares but recognisable. But the squares revolve; create bodies that further disrupt ideals of normality, size, balance, harmony, and symmetry. We are confronted with possibilities of alternative embodiment, other ways of being in the world, a harsher, fragile beauty.



Joey Hateley and Siobhan Rocks performing *diRTy*. Photograph: Nicolas Chinardet. Courtesy <http://disabilityarts.online/magazine/opinion/dadafest-2016-dirty-joey-hateley-gender-joker/>

Intimacy: Touch, Danger and Desire

The dance work of **Claire Cunningham** takes us back to dreams, the things we yearn for, to the potential moments of intimacy in our lives. Claire's dance partners are the crutches she uses to move around in the world, her supports, always by her side, indispensable, solid—but not renowned for speaking. Yet with Claire, they become garrulous, voluble, sharing Claire's desires as an extension of her body. In the short *Ménage à Trois*,⁸ when Claire says "We click!" we see the connections weaving through her crutches to the invisible figure of Claire's, perhaps of our own, desire.

Work by **Sue McLaine** and **Nadia Nadarajah** address the danger of intimacy. In *Can I Start Again Please?*⁹ two women, enclosed in a matching dress sewn together at the skirt, sit side by side, reading from a common script that they slide simultaneously across their laps. One speaks, one Signs, their story one of meanings and misinterpretations, of semantic games and images shifting, as they show growing up in an old house, lonely, no siblings for company. The tale

turns edgy, violence filters in through cracks. We recognise this as a story of hidden sexual abuse and brutality, of the unacknowledged harm faced by many Deaf women across the globe who live with sexual violence, of courts too limited to receive the testimony of their abuse from such wise and witty interpreters. And so it goes on, unpunished. Yet, in bringing the abuse of Deaf women to public notice, it comes into focus, joining with other campaigns to end violence against women, against disabled people.

These two works highlight how moments of touch, whether desired or unwanted, have incredible power. Touch between what is regarded as "abject" individuals, disabled bodies, creates power, tension, excitement. Saturated with affect, inducing strong emotions, such contact potentially harbours danger, even violence. Although outside the life experience of many non-disabled people, disability art offers the opportunity to see and learn directly through the stories that people tell, enabling a greater understanding of lives as they have been lived by others.

Disabled people are discovering that art is a powerful way to challenge the fear and silences, to speak out against abuse, to heal the scars. And it is also a way of coming to know our own widely different bodies and emotions, of acknowledging our inherent beauty, of welcoming the myriad ways of being sexual that do not fit within the normative, fixed, straight lines of conformity, but that curve and crease, that have flow and taste, scent and movement.

Addressing Pain. *Corpo Illicito* by **La Pocha Nostra** was performed at DaDaFest 2010,¹⁰ with a core of actors who were joined by the audience of disabled people and their companions. The bare body of an indigenous mestiza woman lay on a table, marked into regions by acupuncture flags, their placement chosen by the audience. The exception was the USA flag, which flew on her forehead, highlighting the point of control—in acupuncture of pain, visually of power. The guerrilla chief, the “commander,” wandered past; absent-mindedly fondled her. She represented the bodies of all the women who had been controlled, physically, emotionally, sexually, by the excesses of male power and colonisation, of racial hierarchies and gendered norms. Later in the performance, the entrance of a bearded *hijra*¹¹ and their female partner challenged expectations of sexuality and gender through the love they demonstrated for each other. The *hijra* held their feet above burning candles, an implicit sign of all the painful, disabling moments they had lived through, challenging us to pull their feet free of the burn, free of the control and agony they lived with.

A brilliant play covering a world of intersectional prejudice, *Corpo Illicito* places the audience within the performance, where they become aware of their own relation to others’ deeply embodied pain. They are exposed to

the fluidity of intersectional sexuality and to the prejudice and discrimination meted out to disabled people and others living outside of the norms. Yet the format offers a chance to be involved in challenging the prejudice, to join with others in developing solutions.

Photo Credit: DaDaFest



A performance at our most recent DaDaFest 2016, of “*diRTy*” by the trans artist **Joey Hately, the Gender Joker**,¹² offered us an insight into the journey she? or is she a he? took towards transition. It linked powerfully with the campaign run by trans and intersex activists at AWID¹³ 2016 against body pathologisation,¹⁴ a critique of the ways in which medicine attempts to normalize all sexed and disabled bodies, regardless of individual desire. Sharing the deep psychosocial impact linked to Joey’s sexuality, arising from distressing experiences in early life, not from the gender change, “*diRTy*” also revealed the hate directed at the Gender Joker in this latter period. Supported by a BSL Sign artist and interpreter **Siobhan Rocks**, Joey staged a bravura performance playing a child, a priest, a “respectable” man and a woman sex worker, represented by single articles

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of clothing, film, Sign and spoken word. Travelling from past fear and sadness, towards hope and desire, the emotional connection established by the performance was evidenced in a post-show discussion where the disparate audience shared stories of trans, queer, gender-fluid and cross-dressing events they had experienced within their own lives and families. Many, for the first time, took the chance Joey offered to engage with personal questions about the fluidity of gender, of sexuality and of disability. Performances such as “*diRTy*” bring what is silenced into the open, make visible what is hidden, speak so that claims can be heard. Recognising the commonalities shared, they challenge discrimination and demand fair treatment and justice, in solidarity, for disabled, gender fluid, and queer people together.

Disabled people are discovering that art is a powerful way to challenge the fear and silences, to speak out against abuse, to heal the scars. And it is also a way of coming to know our own widely different bodies and emotions, of acknowledging our inherent beauty, of welcoming the myriad ways of being sexual that do not fit within the normative, fixed, straight lines of conformity, but that curve and crease, that have flow and taste, scent and movement.

Conclusion. The potential for an end to the stigma and shame that many disabled artists experience and recognize in others lies at the core of their powerful dreams and hopes for intimacy, eroticism and companionship. Most of all, they harbour hope for justice, a hope that is shared with their audience who see

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the work. This shared dream for change that emerges from creating and viewing disability art, touching as it does upon people's deepest desires, is an important part of why the work of DaDaFest can so powerfully act to uncover deep desires about sexuality.

As individuals reach out and use art to make relationships across differences, build connections that allow them to understand more of the injustice others face within disability, sexuality, and its related intersections, and in turn respond to these through creating and sharing art, they discover ways to build alliances of people campaigning for disability rights and justice. And together these groups connect to create a more just and equitable world.

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2. Anne Finger, "Forbidden Fruit: Why shouldn't disabled people have sex or become parents?" *New Internationalist*, No. 233 (1992), <https://newint.org/features/1992/07/05/fruit>.
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attribute added on to a pre-existing individual, as used within the UN Convention on the Rights of Persons with Disabilities (UNCRPD). I adopt here the UK usage, unless adopting others' usage or speaking of UN issues.

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spotlight

WOMEN WITH DISABILITIES: Parenting and Reproduction

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Multiple narratives constitute ideas of motherhood and childhood. These emerge from the diverse experiences of parenting. However, in popular culture, there is a tendency to idealise and naturalise parenting into a one-size-fits-all category, often accompanied by the image of a young, non-disabled woman as a parent. Any attempt to disrupt this idealized notion, and make visible the complexities that accompany both motherhood and childhood, remains a challenge. Women with disabilities have played an important role in disrupting this singular narrative.

Over the past decades, the emergence of LGBT, disability, intersex, and sex workers' rights movements has contributed to the emergence of a counter-narrative that challenges some of the stereotypes associated with parenting, in particular, motherhood. This has been accompanied by the rapid advancement of technologies for assisted reproduction. These technologies have served to profoundly alter the mechanics of reproduction and, in the words of Adria Shwartz, ". . . shaken the very foundations of our notions of motherhood . . . the naturalness of the reproductive process has been dramatically altered . . . the associative

link between women, fertility and motherhood is being eroded, if not broken, in the laboratory."

According to the 2011 Census of India, of the total population of persons with disabilities (21 million or 2.1% of the total population) close to half report being unmarried. Unsurprisingly, the percentage of women with disabilities that report being unmarried is more than that of men. In India, where the marriage market is segmented by many parameters such as caste, religion, and ethnicity, to name a few that serve as selection or exclusionary criteria, it is not hard to see why disability would

constitute an important parameter. An online matrimonial site conducted a survey in 2011¹ about young people's views on marriage and suitable partners. The survey confirms that ableism continues to be an important parameter in the selection of a marital partner. In the survey, 59% women and 48% men said they will not marry anyone with a physical disability. About 34% women and 37% men said it would depend on the situation and extent of the disability. Only 7% women and 15% men said that they would marry someone with a physical disability.

Marriage remains the key axis within which most people, including those with disabilities, realise their aspirations with regard to parenting. Women with disabilities face severe limitations in negotiating the right to marry. This has consequences for related decisions on child bearing and parenting.

In India, marriage remains the primary institution through which young people realise their romantic and sexual aspirations. Young people with disabilities are no exception. In response to the need for them to find partners, niche matrimonial sites such as Wanted Umbrella, India's first match-making and matrimonial site for the differently abled, has been launched. A second site that is increasingly accessed by women with disabilities is Inclov. Technology-based solutions such as these have helped to open up spaces for young people with disabilities to meet people, although these spaces are contingent on English language proficiency and access to technology. However, technology does create opportunities to disrupt the

"isolation" and "alienation" that young people with disabilities often experience in forging relationships.

Many disabled people's organisations (DPOs), like the Delhi Foundation of Deaf Women have emerged as viable third parties where gatherings are organised with young people with disabilities to meet and explore marriage alliances. In addition, many state governments in India have introduced cash transfer schemes that provide incentives to people who marry a person with a disability. This scheme has had a mixed response from the disability community with some criticising it as further stigmatising those with disabilities. Others believe that the scheme can help empower those with disabilities, particularly women.

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The other fault line that profoundly impacts on the decision of women with disabilities to reproduce is the domain of laws. A wide spectrum of laws limits the legal capacity, autonomy, and choice of women with disabilities, particularly those with intellectual and psycho-social disabilities. The decision to reproduce or not is important to analyse through the prism of consent. Carole Vance, a noted U.S. academic, has written extensively on the role of consent as an important part of sexual interactions and notes that though there are complexities with regard to always being able to determine if a person's sexual interaction is consensual, the standard of consent has become widely accepted and enshrined in laws. However, for women

with disabilities, consent standards still remain a widely debated issue and many national laws often include a disability exception when guaranteeing women's right to choose.

Two examples from India demonstrate how the standard of consent remains undermined for women with disabilities. In the first case, the Supreme Court of India, some years ago,² upheld the right of a girl with intellectual disability to give birth to a child. Some, including many from the disability rights movement, perceived this to be a welcome judgement. However, in reading the fine print of the language of the judgement, others highlighted the fact that the Court's decision was based on an interpretation of the rights of the child and not necessarily the rights of the woman. To quote Shruti Pandey, women's and human rights activist, as cited in an article by Mahabal, "If the [Supreme Court of India] has said this woman wants to go ahead with the pregnancy, in principle I would support the decision. Every woman, including women with mental disabilities, has a right to bear children. But if the court says it is the right of the child to be born/not to be killed, and so the pregnancy must go on, that is hugely problematic." In the same article Mahabal talks about a much-criticised incident in India during the 1990s when hysterectomy was performed on 17 mentally challenged girls below 18 years. The girls were lodged in a mental health institution. In this instance, the state government took a unilateral decision to control the girls' reproductive rights. The professionals involved in doing this did not perceive this as a gross violation of human rights, but rather justified their actions as having been done in the best interests of the girls. When it comes to the reproductive decision-making of women with disabilities it is evident that Courts and the State play

an intrusive role; often hidden behind the protectionist discourse is a complete disregard for the right to consent of women with disabilities.

Parenting, and in particular motherhood, is linked to the dominant narrative of being a protector and caregiver. What constitutes the capacity to look after a child is subjective, though laws are often used to define and interpret this in ways that mirror the dominant societal discourse about a parent-child relationship and more importantly, what it takes to be a “good mother.”

In the case of women with disabilities the need to address their right to parenting and reproduction needs to be looked at as a continuum and how society and law play a profound role in placing constraints through their life cycle. To elaborate further, decisions about the right to parent for those with disabilities take place in childhood (at the time of puberty) often as part of a series of protectionist measures and can often take the extreme form such as sterilisation and hysterectomy. In its more benign form it manifests in the way families, caregivers, and other institutions “permanently” infantilise women with disabilities and accord no recognition to their evolving sexuality.

This final segment takes us back to where this article began in highlighting the diverse ways technology is altering choices around reproduction. The accelerated pace of technology proliferation as well as its diffusion into the everyday lives of women needs to be understood both in terms of its liberatory potential for women with disabilities as well as the profound dilemmas that they pose. Pre-natal testing is one of the most contested sites where this dilemma manifests. The increasing possibility of being able to screen for various disabilities can result in undue pressure

on women with disabilities to undergo prenatal testing during the course of their pregnancies. Judging the quality of the foetus remains strongly embedded within a medical discourse. Even as access to abortion remains restricted and abortion itself stigmatised, access to disability-selective abortions remains normalized and encouraged by providers. The idea that a woman with a disability cannot be a “good mother” and caregiver remains strongly entrenched as a societal norm. Families and caregivers deploy a raft of protectionist measures, from the more benign confinement within the home to the more extreme hysterectomy and sterilization, based on a belief that women with disabilities are incapable of providing consent and pregnancy can only be the result of non-consensual sex, an act of violence. It is worth pointing out that this can vary depending on the type of disability.

“If the [Supreme Court of India] has said this woman wants to go ahead with the pregnancy, in principle I would support the decision. Every woman, including women with mental disabilities, has a right to bear children. But if the court says it is the right of the child to be born/not to be killed, and so the pregnancy must go on, that is hugely problematic.”

Shruti Pandey
Women’s and Human Rights Activist

In discussing reproduction and parenting for women with disabilities the idea is not to reify their desire to parent. It is important to note that not all women, including women with disabilities, want to reproduce and embrace motherhood. Women’s choice to undergo an abortion,

be a surrogate, or hand over new-born children for adoption, reflect the complex ways women view reproduction and motherhood.

The continuum of experiences of women with disabilities through childhood and adulthood as mediated by society, law and institutions—some of which have been addressed in this article—remains both a complex and contested domain that mediates the experience of reproduction and parenting of women with disabilities. The one thing that can transform these experiences is to constantly seek to advance a framework and understanding of consent that recognizes the agency of all women and enables them to exercise their rights.

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REMOVING COMMUNICATION BARRIERS: Accessing Comprehensive Reproductive Health Services For Deaf Women and Girls

The World Health Organization (WHO) defines health as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.”¹ Reproductive health addresses reproductive processes, functions and system at all stages of life.² Underlying the concept of reproductive health is a tacit understanding that there should be equity for people to be able to have a responsible, satisfying, and safe sex life, and that they have the capability to reproduce and the freedom to decide if, when, and how often to engage in sexual activities.

Individuals, however, face inequities in accessing reproductive health services, whether as a result of socioeconomic status, education level, age, ethnicity, religion, disability, gender, sex, and/or resources available in an individual’s environment.³

For deaf people, the provision of quality healthcare services and health education programmes is often compromised due to language barriers. When talking to deaf people on topics related to reproductive health, it becomes apparent that whereas people’s decisions to avail themselves of medical treatment or health education may be dependent on the severity of the condition and/or accessibility of the service provision, this choice significantly diminishes for women when it comes to reproductive health issues, even more so if she is deaf and pregnant.

For deaf people, the provision of quality healthcare services and health education programmes is often compromised due to language barriers. When talking to deaf people on topics related to reproductive health, it becomes apparent that whereas people’s decisions to avail themselves of medical treatment or health education may be dependent on the severity of the condition and/or accessibility of the service provision, this choice significantly diminishes for women when it comes to reproductive health issues, even more so if she is deaf and pregnant.

The importance of providing language accessibility in the health sector is best exemplified by the following experience. Whilst undertaking research, I met a 19-year-old deaf woman who informed me with some pride that she had a sub-dermal implant as a means of birth control. In response to questions about her choice, knowledge about the availability of contraceptive methods, medical advice sought, and knowledge of “safe sex,” it was evident that she had no idea about contraceptive methods and sexually transmitted diseases or how to protect

herself using alternative methods. She said that the implant was her mother’s choice. She also explained that she couldn’t communicate with her mother in detail about issues such as birth control because her mother could not communicate with her in sign language.

In my work experience, I have encountered many deaf people in the same situation lacking the knowledge that a contraceptive implant does not protect against sexually transmitted diseases including HIV/AIDS. This primarily arises from the fact that a majority of deaf children are born to parents who can hear, have no knowledge of sign language, and therefore cannot communicate with their children on vital life issues.

Medical practitioners, unable to communicate directly with their patients, also do not seek the consent of deaf patients and instead act according to the guardian’s wishes, thus paying little regard to the individual’s knowledge and choice of reproductive health and right to have a responsible, satisfying and safe sex life.

Still being an involved leader on various training programmes and projects on health services, including on reproductive health, I feel that the communication barrier and its relationship to issues of health and well-being create problems for deaf individuals. For example, it limits their access to and realization of equal rights to healthcare in comparison to their peers who can hear. It is generally recognized

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that children and young people who are deaf are disadvantaged by the lack of access to good health services, including reproductive health services, mostly because the stakeholders in the health service lack knowledge on sign language.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) specifies that state parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.⁴ It also places an obligation on governments to recognise the importance of sign languages and promote their use.⁵ Thus, the UNCRPD recognises that sign languages share an equal status with other spoken languages.⁶ Therefore, sign language should be recognised and promoted as deaf people have an equal right to obtain health services and information without any discrimination or disadvantage.

Unfortunately, legislation is not always translated into effective implementation by national governments. Thus, progress has been slow around the world. According to the World Federation of the Deaf, in 2017, only 41 countries of the 193 member states of the United Nations were estimated to legally recognise sign language in their countries.⁷

Even when there is legal recognition, the status may differ across countries; in some countries, the national sign language is an official state language, whereas others have separate sign language acts and acts mentioning the status of sign language, such as constitutional recognition, general language legislation, sign language laws or acts, national language council recognition, or the recognition of sign language in the disability legislation acts. Although official recognition of sign language is not directly related to health services, it is directly related to every detail of the lives of deaf

people. Therefore, healthcare providers must recognize and respect sign languages as equal in status to spoken languages and should deliver reproductive health services through sign language. The use of different languages enhances effective delivery of public services and improves the access to and quality of healthcare and reproductive health services for particular target groups. Thus, it can also save lives. Since communication is a two-way process, authorities should not impose the use of a single, official language on everyone, in all situations.

To conclude, I recommend to government agencies and non-governmental organizations working in the health and reproductive health field to ensure all medical services are based on the premise of respect for human diversity and that reproductive health policies recognise language differences, including sign language. Greater attention should be paid to ongoing contact and communication with deaf girls, young individuals, and their families, to ensure they attain full access to comprehensive reproductive health and services.

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SETTING THE AGENDA ON THE SRHR OF DISABLED WOMEN IN SRI LANKA¹

Political Context. Sri Lanka underwent a protracted civil war from 1983 – 2009, which led to a high incidence of impairment and inadvertently stratified disabled people in terms of gender and civilian-veteran status. State initiatives to meet the needs of veterans became a catalyst for disability policy reform and service provision. Limited initiatives in relation to the sexual and reproductive health and rights (SRHR) of disabled people can be traced back to efforts to meet the reproductive needs of veterans. The LILI (Light to Life) project,² set up by the Family Planning Association (FPA) in 2009, was a veteran-led sexual and reproductive health (SRH) service that is now partially available to disabled civilians. Efforts have been made under the radar in the past, primarily in the personal capacity of advocates at the FPA, to conduct SRHR workshops for disabled people in collaboration with community organizations. However, these have been suspended due to lack of funding and exclusion of disabled people's SRHR from state and non-state agendas.³ Disabled civilian women in a post-war setting are largely excluded from SRHR discourse and consequently from related legal rights. They are also highly under-represented in leadership and agendas of Disabled People's Organizations (DPO).⁴ Their needs and rights, including SRHR, are subsumed by DPO priority areas like access and livelihood. This hierarchical approach to rights often leads to the exclusion of SRHR from transformative agendas. It is reflective of the general sexuality taboo that has led to resistance towards

perceiving SRHR as human rights in Sri Lanka. This signals the need to bring women to the forefront of the disability rights landscape and in doing so to build strategic alliances with both the women's and SRHR movements.

Sexual and Reproductive Health (SRH) in Sri Lanka is closely enmeshed within larger cultural frameworks like marriage and is regulated through socio-cultural discourses like stigma and shame. Marriage is the primary gateway for accessing mainstream sexual and reproductive health services for most women in Sri Lanka. Unmarried women who are sexually active often have to claim that they are married in order to access services.

Cultural Context. Sexual and Reproductive Health (SRH) in Sri Lanka is closely enmeshed within larger cultural frameworks like marriage and is regulated through socio-cultural discourses like stigma and shame. Marriage is the primary gateway for accessing mainstream sexual and reproductive health services for most women in Sri Lanka. Unmarried women who are sexually active often have to claim that they are married in order to access services.

spotlight

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Disabled women are stereotypically associated with non-sexuality, fragility, and innocence. The pseudo-Buddhistic notions of *hiri othap* (shame and fear) discursively regulate the fulfilment of duties and morality in Sri Lanka. Hence social status and approval are of paramount importance. Shame is linked to karmic understanding of disability in a Sri Lankan Buddhist context. Disability is seen as a stigma that leads to diminished status and social disapproval. Marrying a disabled woman may lead to the stigmatization and devaluation of the husband and his family, which acts as a deterrence to such marriages. These beliefs render disabled women "unmarriageable" in popular view. This is one of the key reasons why disabled women are automatically omitted from mainstream reproductive health discourses and legal rights.

During the course of Sri Lanka's 26-year civil war, women experienced abandonment upon acquiring impairments. Others had to navigate the intersectional stigma of being disabled war widows. In the case of psychosocial disabilities, there are accounts of women who have been viewed as hypersexual or unfit to perform their marital duties and were forcibly incarcerated by families. The diminished marriageability of disabled women in Sri Lanka is a manifestation of systemic oppression brought about by exclusionary institutional practices as opposed to inherent undesirability. They may have informal relationships but are often precluded from marriage, which is the

primary avenue for sexual validation and the sanctum of reproduction. Hence, they are denied socially valued gendered roles like wife and mother. This has a significant impact on their experienced and perceived worthiness and social standing and their ability to exercise their SRHR.

A DPO representative⁵ said that local men in his constituency try to convince disabled women to enter covert sexual arrangements claiming “it’s the best they will get.” These casual arrangements make women particularly vulnerable to exploitation. They have limited or no access to contraception and are susceptible to contracting STIs while falling outside the radar of the SRH sector.

In a society where women who experience rape and disabled women who reproduce are heavily stigmatised, sterilization and forced abortion are seen as a convenient means of brushing both under the carpet.

Care Economy. Many disabled women in Sri Lanka are institutionalized in charitable care homes.⁶ These institutions mediate their rights and their movement; privacy and autonomy are subsumed by institutional guardianship. If not institutionalized, many live as wards of their families. This is primarily due to the lack of state services, lack of access to the public sphere, and a dearth of services for independent living. It is also an outcome of a culture that heavily relies on family-based care.

Given the assumed un-marriageability of disabled women, they may become pregnant outside wedlock under a range of circumstances, which compounds the associative stigma for families. Hence,

they are unlikely to receive formal and adequate maternity care.

Even those who become pregnant within wedlock are viewed with suspicion. There is a biomedical hysteria regarding the potential transmission of undesirable impairments through the reproductive bodies of disabled women. The genetic perpetuation of impairments in families compounds shame and stigma. There are concerns regarding disabled women’s fitness and capacity to become mothers and parent children. Hence the pregnant disabled woman is viewed as adding to the family care burden.

In a society where women who experience rape and disabled women who reproduce are heavily stigmatised, sterilization and forced abortion are seen as a convenient means of brushing both under the carpet. Although there is a 20-year sentence stipulated for institutional abuse, there is no transparent system of accountability for the protection of those under the guardianship of charity homes.⁷ This renders disabled women in such homes and those dependent on the larger care economy highly vulnerable.

Accessibility. Given the taboo surrounding sexuality, any content regarding reproduction, leave aside sexuality education, is glossed over in Sri Lankan public and private school curriculums. A representative of the Sri Lanka Federation of the Deaf said that reproduction was completely excluded from the curriculum at the special school she attended on the basis that it was deemed irrelevant to hearing-impaired students.⁸ This reflects the assumed non-sexuality and un-marriageability of the students, as well as fears that they would be corrupted through exposure to a taboo subject, given the stereotypes about their purity and innocence.

It is only recently that the disability movement in Sri Lanka has begun to address the issue of sexual violence. SRHR is yet to be engaged with meaningfully. While this initial dialogue on sexual violence is encouraging, the framing of sexuality primarily in terms of vulnerability may detract from a conceptualization of sexuality and reproduction as universal rights.

Most facilities, including private SRH clinics, remain inaccessible to those with physical impairments. The representative of the Federation of the Deaf⁹ said that communication was a key barrier for hearing-impaired individuals when accessing SRH-related information and services. There is a dearth of sign language interpreters in Sri Lanka, and most healthcare facilities are inaccessible on that basis. The representative narrated how a deaf woman known to her died shortly after giving birth, as she was unable to communicate high blood pressure symptoms to the medical staff.

Disability Movement. It is only recently that the disability movement in Sri Lanka has begun to address the issue of sexual violence. SRHR is yet to be engaged with meaningfully. While this initial dialogue on sexual violence is encouraging, the framing of sexuality primarily in terms of vulnerability may detract from a conceptualization of sexuality and reproduction as universal rights. What is required is a balance between addressing vulnerability and developing sex-positive rights frameworks. This entails building alliances with the broader SRH sector, which requires active, community-level outreach and recognition of disabled women as a key constituency. Efforts are

currently underway to establish a Women with Disabilities wing by the Disability Organizations Joint Front (DOJF),¹⁰ the national umbrella organization for DPOs, to facilitate such collaboration.

Legal Framework and

Recommendations. The Sri Lankan government acceded to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in February 2016. A draft Disability Rights Act, which reflects the state's obligations to the CRPD, is currently under review. Article 19, sub clause 3 states that all disabled people should have access to reproductive and family planning

information and services to exercise their choices. This sets a strong foundation for the assertion of the SRHR of disabled people and provides a basis for legal reform. It is imperative to address these barriers through affirmative measures like sensitization, family support, access to information and facilities, and the regulation of institutions. Such interventions are a vital aspect of the state's compliance with the CRPD, which will give efficacy to formal legal reform. It is also imperative to prioritize the SRHR of disabled women in state and non-state agendas, especially in terms of funding, resource allocation, and legislative reform.

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SUCCESS IN ADVOCACY: Positive Changes in Law in India

Girls and women with disabilities are considered soft targets and are more vulnerable to exploitation compared to their non-disabled counterparts. Most such incidents go unreported to the police, with victims already stigmatised because of their disability, refraining from doing so for fear of further stigmatisation. Besides, society at large, including law enforcement agencies, does not take such crimes against disabled women seriously.

The justice delivery system has also failed the disabled in many cases. A study of judicial decisions indicates that in most cases disabled victims of sexual abuse are either not examined in court or their testimony is not recorded. Even when recorded, they often do not meet legal requirements, thus making them redundant. There have also been cases

earlier where testimonies given through sign language have been devalued.¹

The public outcry following the gang rape in Delhi of a young paramedical student in December 2012, led to the constitution of the Justice J.S. Verma Committee. This three-member committee was entrusted with the task of recommending changes to criminal laws dealing with sexual assaults. This, for the first time, provided the National Platform for the Rights of the Disabled (NPRD)² and other disability rights organisations an opportunity to draw attention to specific concerns of women with disabilities.

Suggestions to the Verma Committee.

The NPRD, in its submissions to the Committee, highlighted the difficulties encountered by disabled women at

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The justice delivery system has also failed the disabled in many cases. A study of judicial decisions indicates that in most cases disabled victims of sexual abuse are either not examined in court or their testimony is not recorded.

each stage of the criminal-legal process, right from filing the police complaint to testifying in court during the trial.³

We pointed out that each disability has a unique issue, when it comes to experiencing sexual attacks: a blind girl is unable to see the perpetrator; a speech-impaired woman will find it difficult to communicate the agony that she has been through; a girl with an intellectual disability may be unable to even comprehend that a violation has taken place; the complaint of a woman with mental illness is generally shrugged off.

We also sought provisions similar to those existing under the rules framed under the Protection of Children from Sexual Offences Act 2012 (POCSO) to deal with adult victims of sexual assault. The rules had provision for making available the services of sign language interpreters, special educators, translators, and experts, wherever needed, depending on the needs of the victim.

We informed the Committee of the need for training/sensitisation of police officers, and judicial and medical professionals, on issues concerning women with disabilities and the violence they face; the drawing up of Standard Operating Procedures (SOP) for investigating cases of sexual assault on women with disabilities; and the need to set up monitoring and regulatory mechanisms for institutions where disabled women are lodged, given the rampant neglect and abuse within these institutions.

Finally, we flagged the need to maintain disaggregated data of sexual assaults on disabled women by the National Crimes Records Bureau. Such data would help comprehend the scale of these crimes and support advocacy work.

Amendments to Criminal Laws. The Verma Committee for the first time provided an opportunity for disability rights groups to place the issue of sexual assaults from the perspective of

women with disabilities. The Committee recognised the problems faced by women with disabilities in accessing the judicial system and the need to have laws to make this possible. Many of the suggestions made by the NPRD and other disability rights organisations found reflection in the recommendations of the committee, some of which have now become part of law.

As per the amendments made to criminal laws, when a physically or mentally disabled woman lodges a complaint of rape or “outraging of modesty,” such complaint shall be recorded by a woman police officer at the residence of the complainant, or wherever she is comfortable. Throughout the entire legal/judicial process, right from filing of the complaint to the recording of the statement, a special educator or interpreter, depending on the needs of the complainant, would be provided. Additionally, this entire process has to be videographed.

The Committee also recommended setting up of oversight mechanisms under the High Courts in each state to monitor institutions where disabled women are lodged. The Committee recognized that sex education must also be provided to disabled children and young people by professionally trained teachers and caregivers, to ensure their safety and holistic development. The Committee while recommending the setting up of Sexual Assault Crisis Centres at hospitals said that counsellors present in these centres should be professionally qualified to address the needs of disabled victims of sexual assault. In addition, the report of the counsellor regarding the disability of the victim should be part of the medico-legal evidence that is submitted to the court.

The amended criminal law now stipulates that the test identification parade should

be carried out under the supervision of a Judicial Magistrate and it would be the magistrate’s duty to ensure that the disabled victim is allowed to identify the perpetrator of the crime in whichever manner he/she is comfortable, for example, by touching or through voice identification.

As per the amendments made to criminal laws, when a physically or mentally disabled woman lodges a complaint of rape or “outraging of modesty,” such complaint shall be recorded by a woman police officer at the residence of the complainant, or wherever she is comfortable. Throughout the entire legal/judicial process, right from filing of the complaint to the recording of the statement, a special educator or interpreter, depending on the needs of the complainant, would be provided. Additionally, this entire process has to be videographed.

Importantly, “consent” would be treated as invalid if anybody commits a sexual act on a woman who is of “unsound mind,” attracting seven years imprisonment. If a woman who is of “unsound mind” is raped, it would be treated as “aggravated sexual assault” and would attract an additional three years of imprisonment. In both these cases, the term can be extended to life imprisonment and fines can also be imposed.

Challenges Ahead. While the changes to the law are positive and substantial in nature, implementation has been poor. This is substantiated by procedural

and other lapses in cases that state level affiliates of the NPRD have been pursuing. For example, in a case registered by a girl who was speech impaired and intellectually disabled at the Jehangirpuri Police station in Delhi in 2013, a sign language interpreter, rather than a special educator, was requisitioned. There was also a procedural lapse when the statement was recorded at the hospital and not at the residence of the victim. In another case in 2015 in Mangolpuri in North West Delhi, where a girl with an intellectual disability was raped, no special educator was present while her statement was recorded before the Judicial Magistrate. In both these cases the Delhi Vilkgang Adhikar Manch (Delhi Platform for the Rights of the Disabled), an NPRD affiliate, is providing legal support.

In another case in Denkanikotta of Krishnagiri district, Tamil Nadu, in 2015, where a hearing and speech impaired girl was raped, the victim had to be carried by her father on his shoulders for several kilometres to reach the police station and lodge a complaint. Since the police did not arrange for a sign language interpreter, our local affiliate, the Tamil Nadu Association for the Rights of All Types of Differently Abled and Caregivers (TARATDAC)⁴ had to step in and arrange for one. Additionally, there were issues with regard to the manner in which the entire case was handled, which might have led to miscarriage of justice (which was prevented by the constant vigil maintained by TARATDAC). The First Information Report (FIR) did not mention gang rape; this was added only after protests.

The Way Forward. Experiences from these cases indicate that despite positive amendments to laws, constant vigilance and intervention are essential for enforcement. It also highlights the lack of knowledge and sensitivity to deal

with issues related to sexual assault on disabled women and girls.

These positive changes in laws, it needs to be underlined, have come about after years of advocacy, which include representations to the State and the National Commission for Women (NCW), raising the subject at various fora, and finally before the Verma Committee.

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It is essential that advocacy for the implementation of various other recommendations made by the Verma Committee be stepped up with regard to monitoring of institutions where disabled women are lodged. This has also been underlined in the Human Rights Watch Report, 2013;⁵ for instance, this report highlighted the importance of providing sexuality education. Thus, there is a vital need to step up the campaign for sexuality education, improving awareness among care-givers/professionals working among disabled women and the police/judiciary, both with regard to these changes as well as creating more sensitivity to the issues. Lastly, it is also important that as activists we work together with other movements, including the larger women's movement, to achieve better success.

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WOMEN WITH DISABILITIES TAKE ACTION ON REPRODUCTIVE AND SEXUAL HEALTH

W-DARE, The Philippines

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Background. Around 1 billion people worldwide live with disability.¹ People with disabilities face discrimination and prejudice, which contribute to their exclusion from the social, cultural, political, and economic life of their communities. Women with disabilities may also experience discrimination on the basis of their gender, further undermining their ability to realise their rights.²

Women with disabilities experience poor health outcomes across the life cycle, with greater unmet health needs and reduced access to health information, screening, and preventive and healthcare services than women without disability.³ They have particularly poor access to sexual and reproductive health (SRH) programmes. A range of barriers undermines access to SRH services for women with disabilities, and they are often excluded from outreach programmes because of the false belief that people with disability are asexual and do not require sexual and/or reproductive healthcare.⁴ Limited data about disability prevalence also makes it difficult to plan and resource disability-inclusive SRH programmes.

Most women with disabilities live in low- and middle-income countries.⁵ However, there has been very little research done in these settings to increase understanding about the barriers to SRH they experience, or to investigate what might be done to improve their SRH. The W-DARE project in the Philippines is one of the few examples, worldwide, of action research that has

been undertaken to increase access to SRH services and information for women with disabilities.

Overview of W-DARE. W-DARE was a three-year participatory action research project (April 2013 to June 2016) conducted by researchers at the University of Melbourne in Australia and De La Salle University in the Philippines, in partnership with the Likhaan Center for Women's Health, Center for Women's Studies Foundation at the University of the Philippines, and two national Disabled People's Organisations (DPOs)—WOWLEAP (Women with Disabilities LEAP to Social and Economic Progress Inc.) and PARE (Persons with Disability Advocating for Rights and Empowerment). The project was disability-inclusive throughout, with DPOs and women with disabilities involved in developing the research questions; designing research tools; data collection and analysis; designing, implementing, and evaluating subsequent pilot interventions; and disseminating research findings.⁶ This required a substantial investment in capacity building to develop research team members' knowledge and skills in relation to disability, and to ensure women with disabilities were actively involved as co-researchers in the design and implementation of all research activities.

Most women with disabilities live in low- and middle-income countries. However, there has been very little research done in these settings to increase understanding about the barriers to SRH they experience, or to investigate what might be done to improve their SRH. The W-DARE project in the Philippines is one of the few examples, worldwide, of action research that has been undertaken to increase access to SRH services and information for women with disabilities.

Documenting the SRH Needs and Experiences of Women with Disabilities.

In the first phase of the project, the W-DARE team conducted a mix of quantitative and qualitative data collection activities to establish a baseline picture of disability prevalence and access to SRH services for women with disabilities.⁷

Quantitative data collected aimed to establish the prevalence of disability (including physical, cognitive, sensory, communicative, and psychosocial disabilities) in the community; and the well-being and access to the community of people with disability (including access to SRH services) compared to respondents without disability. We found that disability prevalence was higher

than had been previously reported, with 6.8% of adults in Quezon City (a densely populated urban district) and 13.6% of adults in Ligao City (a rural and peri-urban district) reporting some form of functional limitation; that prevalence of disability increased with age; and that it was significantly higher amongst those with no schooling. People with disability also reported significantly lower well-being and lower access to all aspects of the community, including health services, than people without disability.⁸

Qualitative data collected aimed to explore the sexual and reproductive experiences of women with disabilities, including experiences with health services, as well as the perspectives of service providers, partners, and family members. We found that women with disabilities had difficulty accessing SRH services, and if they could access services, often received poor treatment. Barriers to SRH for women with disabilities included health service providers' lack of knowledge and skills in relation to disability, and some service providers' prejudiced attitudes and discriminatory behaviours towards women with disabilities seeking SRH care.⁹ Many SRH facilities were reported to be physically inaccessible to women with different types of disability, and women with disabilities and their families have poor SRH knowledge and limited awareness of services. Women who had communication impairments, were deaf, and had intellectual disability and/or psychosocial disability, had particular difficulties accessing information about SRHR. The cost of services, transport, and sign language interpreters present an economic barrier to SRH for women with disabilities. In addition, reports of sexual and physical abuse of women with disabilities were common, and this violence was found to cause physical and mental health problems, including poor SRH, and reduced access to SRH services.¹⁰

In response to these findings, the W-DARE team designed and implemented a programme of pilot interventions to learn more about what might be effective in increasing access to SRH for women with disabilities.

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Improving Access to SRH Information and Services for Women with Disabilities.

The initial W-DARE findings highlighted that there were barriers to SRH for women with disabilities on several levels. It was clear that there is a need to increase the supply of high quality SRH interventions to women with disabilities, and to increase demand for such services. It was also clear that most women with disability have limited ability to travel to access specialist services in a limited number of locations, reinforcing the importance of working with local government to create enabling local environments.¹¹ The qualitative data, in particular, highlighted the impact of prejudice and discrimination on the health of women with disabilities and the delivery of SRH services, so interventions are also required to change attitudes across all aspects of society in the Philippines.

In response, a range of pilot interventions were implemented through the W-DARE programme. Demand-side interventions involved working with women with disabilities, their families, and carers, to increase awareness and uptake of SRH services, and training a group of women with disabilities to facilitate peer-support groups. These groups, known as Participatory Action Groups (PAGs), aimed to increase SRH knowledge and awareness of rights and of services, among women and girls with disabilities.¹² Supply-side interventions involved working with health facilities, SRH service providers, and those responding to violence, to increase access to services by addressing attitudinal, communication, and physical barriers (in particular) faced by women with disabilities. The W-DARE team worked with local government departments to create a more supportive environment for these interventions; to link women with disabilities into existing organisations in their communities; and to foster on-going support for the SRHR of women with disabilities among local decision-makers. Participants in the PAGs worked with the research team to develop a series of short advocacy films to create awareness of the rights and capacities of women with disabilities. With the support of the project, women with disability who had been involved in the PAGs or as co-researchers began advocating to government and international donors for appropriate policy and resourcing. Many of these women continue to work to increase public awareness of the rights and capacities of women with disabilities; to decrease prejudice and discrimination; and to ensure that the perspectives of women with disabilities in relation to health and development are heard by policy-makers.

Reflection on the disability-inclusive and participatory approach used throughout the W-DARE project found that there was a range of benefits as well as

spotlight

challenges with this approach. Key challenges included establishing trust with diverse research partners in the context of a polarised national debate around reproductive health, building genuine partnerships between unequally sized and resourced organisations, and the extra resources required to facilitate the genuine inclusion of women with disabilities in the research. Benefits included the development of new capacities to conduct disability-inclusive research (reported by women with disabilities and academic research partners); the co-construction of new knowledge about the SRH of women with disabilities; and the opportunities for partners to take practical action to improve women's access to SRH information and services.¹³

Key challenges included establishing trust with diverse research partners in the context of a polarised national debate around reproductive health, building genuine partnerships between unequally sized and resourced organisations, and the extra resources required to facilitate the genuine inclusion of women with disabilities in the research. Benefits included the development of new capacities to conduct disability-inclusive research (reported by women with disabilities and academic research partners); the co-construction of new knowledge about the SRH of women with disabilities; and the opportunities for partners to take practical action to improve women's access to SRH information and services.

Policy and Programme

Recommendations for Improving the SRH of Women with Disability. Analysis of W-DARE's design, implementation, and research findings, suggests that upholding the SRH rights of women with disabilities in the Philippines will require:

- increased availability of disability-related data
- monitoring and supporting compliance with existing legislation and policies
- differentiation between the SRH needs of different women with disabilities
- recognition of the impact of violence and abuse on women with disabilities
- building capacity of the health, disability, and social welfare sectors
- building capacity of women with disabilities, their representative organisations, and families
- regular forums that bring relevant agencies together with women with disabilities for planning, service monitoring, and advocacy.

Efforts to ensure that women with disabilities can realise their right to SRH must involve service providers, policy-makers, and researchers working closely with women with disabilities. This requires significant investment of time and resources to enable meaningful participation and build trust. However, the experience of the W-DARE team—including women with disabilities, SRH service providers, and academic researchers from the Philippines and Australia—suggests that such an investment will not only lead to better evidence to inform policy and practice, but that it can also lead to concrete change in the lives of women with disability.

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The Gift

*Caged for so long,
you take less space
you speak softer
you try to look prettier*

*But yours was a wildness
Can you contain
a river in a tin cup?*

*You are crazy, he says
Medicates your spirit
to tame*

*But can the bulbul
who soars free
sing in captivity?*

*Your feathers fell
The river ran dry
Your song, a mere croak*

The cage was home

*One day, the cage opened
He found another
river to swim in,
another forest
to wander in*

*Terrified by this gift,
you stayed in the cage
until you started
loving yourself*

*You are the glint of sunlight
on a pickerel's tail
You are the curve
of an unknown path*

*You are your own
perfect gift. You are
your own perfect
gift.*

DISABILITY AND RELATIONSHIPS: What has Technology Got to Do with It?

By **Nidhi Goyal**

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Seven years ago, my life was as depressing as it could get.

I would lie awake at night, sure that the next day would be even worse than the one just gone by. During these sleepless nights, my friend Rohit¹ would silently sit on the other end of the phone with me, keeping me company while I lay miserably awake. One such night, he asked me a strange question: “Will you come for a film with me?”

In no mood for jokes, I irritably reminded him that we were not in the same town, and that in any case it was past midnight, and no cinema hall would be open so late.

Rohit asked me to join him on Skype. And reluctantly, I did. When the call connected, I heard a faint excitement in his voice, but I was too depressed to notice it till the music began to roll. He smiled, and said, “It won’t be as interesting as the musical you saw but this has its own beauty.”

Saying this, Rohit played a film, but in a version which was thoughtful like him, a version with audio-description.² The film was *Legally Blonde*, but both Rohit and I are legally blind. I remember easing into my bed to watch the movie, with Rohit’s presence on Skype as warm as a physical hug. I could hear his laughter at the same moments I cracked up, we felt each other’s silences during tense moments and with my earphones plugged in, I soon fell asleep.

Rohit was and continues to be “just” a friend, but that night, for a few surreal moments, I thought, “What if this was something more?” And although it wasn’t meant to be between us, I’ll always

remember that night as the most romantic midnight date I ever had.

Disability can be complex, particularly when you are living in countries like India where accessibility to places and services is lacking. If you are visually impaired, navigating unhelpful Indian public infrastructure with a white cane is tough going, and for women, there’s an added concern of abuse and misbehaviour. As a result, many families—being protective and often over-protective—don’t let their daughters with disabilities step out alone. But sometimes I wonder if I can really blame them.

If a woman is on a wheelchair, she will need assistance to enter a university, a hospital, or access public transport. Thus, she is forced to take help from strangers for lifting, pushing, and holding. She is often accompanied by someone, more often a family member. Or she is left with the option of not going out at all. These restrictive infrastructural and social situations are often combined with stigma. Because disabled women are most times not considered women enough, they seldom find opportunities to meet others, form friendships, and find romantic partners.

Technology, however, has been a miraculous gift for persons with disabilities! Not only has it opened up opportunities for education and employment, but also vital spaces like online social networks to interact with others and form friendships.

For many women with disabilities, technology creates a window to the world,

helps in ending isolation and building relationships with others. However, the relationship with technology takes a while to develop.

When I was diagnosed with my eye-disorder at 15, I didn’t really know how my future would unfold. All I knew was that my life was going to tilt, shift, and alter in ways that I couldn’t fathom just then. Everything, from mundane to special, was going to be layered with the challenge of gradually losing my sight. Perhaps as a teenager, one of my biggest worries was how my friendships, social life, and romance would be impacted by my failing sight...

I was introduced to a screen reading software (assistive technology) that would assist me and be my comrade in arms for reading, writing, accessing the web, and getting through my education and work. At the time though, I was highly irritated with this software. I was supposed to be able to see, not hear my educational material in some stupid robotic voice! Like all teenagers, since I couldn’t alter my situation, I rested the blame and irritation on the voice of the screen reader.

Over the years, my relationship with technology has grown and like any friendship, this is a relationship of support, trust and dependence. My laptop’s screen reader “JAWS,” has an American-accented male voice and I often refer to him as “my man.” He listens to me, and speaks whenever I need him to. I can’t imagine living without him, even for a day. He enables me to check my emails, connect with the world through Facebook, share my thoughts on Twitter, work on my

research, mark my calendar, read my novels, and so much more. The only real threat to my relationship with him is the British-accented voice-over software on my iPhone. Personally, I can't decide who is hotter!

There's a widespread belief that people who are disabled are not desirable. And, with all the "real" issues we have to face, we would never even think of romance or love. We are seen as either depressed individuals, dependent on others for survival, or made into inspirational memes, constantly battling crises and emerging victorious.

This couldn't be further from the truth. Our lives are filled with as much desire for love as a sighted person's, and many of us now have access to technology that increases our participation in the great symphony of flirtations, romance, and life.

Last year, on the insistence of some friends, I registered myself on the dating app OkCupid. A friend helped me select my profile photo in which I'm dressed casually, hanging out by the swimming pool with a coffee mug in hand!

I found a person's profile interesting. His writing was witty and he seemed potentially intelligent from his work profile. He was a runner (I was not, but opposites attract, right?), and the clincher was that he loved books! So, I sent him a message.

The only thing was, I couldn't see his picture; a screen reader cannot read images unless it has a written image description or an alt text. When I scrolled over his image, I heard only silence. I wanted to know what this man I had just messaged, looked like. Over dinner, I excitedly asked my girlfriends to describe him, to be told that his profile picture

was of a nude man! Had I known this, I wouldn't have reached out to him.

Thus, the overarching problem for people with disabilities is accessibility, both offline and online. When it comes to dating apps, it's clear that no one—neither the developers nor the app users—really have us in mind. I wanted to expand beyond OkCupid. Tinder was out of the question since it functions primarily on photographs. I ended up using the app, TrulyMadly. Again, I encountered trouble. TrulyMadly has yes and no buttons on either side of its screen, but neither was labelled for screen readers! Although a friend helped me with the buttons, I forgot after a few weeks, had no idea whether I was saying yes to those I wanted to reject and vice versa, and soon deleted the app. In all of this, my primary irritation was why I should be forced to let my friends know every detail of my dating landscape and how much assistance did I really want in this very private aspect of life? Not much, frankly.

Although the internet and technology have levelled the playing field and increased the social reach for people with disabilities, the truth is that the offline heavily impacts the online. Inaccessibilities are echoed in online spaces, and stigma in people's minds percolates into online interactions, particularly in the romantic landscape. It is not uncommon for conversations to cease once the shield of the online is removed from interactions with disabled persons; it is not uncommon for conversations never to start because the disability is out there in an image, or as a category on the website/app, or as a description. And so the struggles continue...

Yet, this doesn't negate the fact that technology has awarded us many more avenues to get creative, to uphold friendships, to pursue interests, and to

in our own words

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create special moments. It was touching when my concerned visually-impaired friend found and forcefully downloaded an accessible language translation app for my trip to Brazil (because I don't speak Portuguese, and with my visual impairment, gestures and signing for communication becomes impossible); and a very special moment when a friend who was hitting on me put up a picture he wanted me to see with a personalized description—quite impersonal for others. It is thanks to technology that many of us feel just like anyone else our age—more of a human being than just a disabled being!

The end...

Notes & References

- ¹ Rohit is a name changed for anonymity.
- ² Audio description is a pre-recorded soundtrack that describes non-verbal scenes in a movie, which means that you don't need to be able to see the screen.

“WE ARE SEXUAL BEINGS” BRINGING SEXUALITY TO THE FOREFRONT IN MENTAL HEALTH PROGRAMMES

In Conversation with Ratnaboli Ray

ARROW speaks with Ratnaboli Ray, the 2016 Recipient of Human Rights Watch’s Alison Des Forges Award for Extraordinary Activism, and the co-founder and Managing Trustee of the Anjali Mental Health Rights Organisation. Anjali works to ensure the human rights of people with psychosocial disability in India.^{1, 2}

In your years of working in this field, has the terrain of mental health changed in any way?

Until ten years ago, nobody thought of using the human rights lens in the mental health discourse; mental health was seen as a watertight medical compartment.

The second change that has happened is the affordability, availability, and accessibility of mental health services. Mental health services have begun to shift away from institutions and have started to make it to communities. However, it needs to be noted that many of these programmes are largely run by NGOs and civil society. The government is in the process of launching a district mental health programme covering all districts of India. But while the government’s intention is fantastic, there are some implementation challenges, including a big gap between the demand and the supply of psychiatrists and mental health professionals in the country. This is why the training of lay professionals or

barefoot workers is a large component of a successful community mental health programme.

The third change is the emergence of alternative setups like group homes, assistive living, and supported living, beyond institutions and community-based health service delivery. While these are in the nascent stages, such outfits were unthinkable ten years ago.

The fourth change is the improvement in the quality of services, whether in institutions or in the community. The fifth change is the enactment of the new Mental Healthcare Act 2017 which stresses on the rights of persons with mental illness, amongst other progressive clauses.

Over the years, have you seen changes in the way that society views accessing mental health services? How is this tied to stigma and discrimination?

This is a very contentious area. One of the things that Anjali is doing with our community health programme—and also others like Banyan and Sangath—is consciously increasing the help-seeking behaviour of people. For example, we have seen an increase in the help-seeking behaviour of young adolescents even with severe mental health issues.

***Interview conducted by
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However, increasing the mental health help-seeking behaviour of women, including housewives, remains extremely challenging. This is beyond stigma and has to do with barriers related to mobility, with disparity in the time clinics are open and the time women are free, and with women not having enough funds to access services.

Could you expand more on the gender dimensions of mental health? Are the causes and the impact of it different across genders (women, men, transgender people)? In what way?

Certain diagnoses—such as bipolar disorder—are slapped more often on women than on men. This happens both globally and in India. Furthermore, in terms of the infrastructure of mental health establishments in India, spaces for women are more cramped and have much less light and ventilation, as opposed to those for men. The impact of certain medication is also gendered as they may affect women and men in different ways.

“However, increasing the mental health help-seeking behaviour of women, including housewives, remains extremely challenging. This is beyond stigma and has to do with barriers related to mobility, with disparity in the time clinics are open and the time women are free, and with women not having enough funds to access services.”

The mental health fraternity has been the moral and medical gatekeeper, and has pathologised sexuality. For example, a trans person who is transitioning from male to female is treated differently by mental health professionals, compared to a person transitioning from female to male. There is a huge lacuna within the system; since there are no rights-based guidelines, there is a lot of arbitrariness in how mental health professionals deal with sexual minorities. It often depends on how empathetic they will be.

The framing of the mental health establishment, in general, is patriarchal, with the diagnostic criteria based on a male, white, heterosexual bias, and this is also true even in the Indian context. Anything other than that is viewed as a disorder or pathology. It is thus important to consider who is at the centre of psychiatry—it is certainly not a woman, nor a woman of colour, nor a woman of colour who is poor and illiterate, nor a poor, illiterate woman of colour living in a rural area, and most certainly not a poor, illiterate woman of colour living in rural area who is a bisexual or a lesbian. Although homosexuality has been removed from diagnostic nomenclature, attitudes haven't changed.

Can you explain the two different frames: mental health and psychosocial disability? What are the advantages of talking in one frame versus the other?

Whether someone has a psychosocial disability or not is a choice of that individual. I may be suffering from serious mental illness—which could be depression, bipolar disorder, schizophrenia, or any other illness—but whether I identify as someone with a psychosocial disability depends on my own politics and my own choice. Using the psychosocial disability frame also means taking the focus away from the medical identity of the illness, to the social factors related to the illness, as

disability is largely a product of the social milieu we live in. Using this frame will also extend the coverage of programmes and schemes for persons with disability to people with psychosocial disability.

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What are the key issues related to sexuality and SRHR of people with psychosocial disabilities?

People with psychosocial disabilities do not have access to information and services and to privacy, and they experience barriers related to expressing their desires and having relationships.

However, when we say that persons with psychosocial disabilities are asexual, it is not that people in mental health institutions do not have sexual desires, ideation, and wishes. Asexuality is imposed on them because if they are not asexual, then they are pathological. On the other hand, the perception that people with psychosocial disabilities are hypersexual is a myth. In my 25-year career, I have not seen someone who is “sexually hyperactive.” Most people who come to us cannot practice affirmative sexuality because they do not have access to information, contraception, or places where they can build relationships. A lot of them are unemployed (since their mobility is often curtailed), and because most of them are poor, they live in cramped spaces where there is no privacy, not even for self-pleasure.

voices from the global south

We also have to remember that mental health institutions are patriarchal and oppressive. Even after recovery, if women are found to be self-pleasuring, they are labelled as ill and are recommitted to mental health institutions.

Even reproductive health becomes very stressful, because the moment you take medication, your whole reproductive cycle goes awry. There is so much anxiety amongst women around whether they can become pregnant or not, particularly given how important motherhood is considered in South Asia. On the other hand, when they have given birth, the babies are often snatched away from them. I once saw a woman who gave birth in the psych ward whose baby was taken away and given for adoption. The woman was beaten up because the nurses thought she had some illicit love affair since she was found wandering out of the house, but who are they to even ask and judge?

“Using the psychosocial disability frame also means taking the focus away from the medical identity of the illness, to the social factors related to the illness, as disability is largely a product of the social milieu we live in. Using this frame will also extend the coverage of programmes and schemes for persons with disability to people with psychosocial disability.”

Psychosocial disability is experienced throughout the woman's life cycle, especially in relation to reproductive health, such as post-partum depression. Please share your thoughts.

It's true. Post-partum depression is so common, and yet it goes completely unrecognised. Sadness is normalised in

our society, and sadness is so gendered—women will cry—so it goes unrecognised. Society tells you that now that you have a baby, what are you being sad about? You have to suppress your sadness because giving birth is a joyous occasion; that is the construct.

“Even if we are working with the recovery care model (which espouses that people exercise choices), we need to talk about the sexuality of people with psychosocial disabilities. We can’t just choose to talk about housing, livelihood, to be symptom-free, and not talk about relationships, intimacy, romance, and pleasure. That’s totally contradictory.”

Where can people with psychosocial disability access information on sexuality and sexual and reproductive health and rights? Is it offered in mental health institutions?

Generally, peers are the sources of information, and therefore these are all half-baked; then there is pornography, which can also be unreal.

Sexuality education is not offered in institutions because people with psychosocial disabilities are perceived as low-risk. There is a lot of curtailment and careful separation between male and female wards. There is no sexual policy for patients in institutions. In fact, one of our long-term objectives of working with the sexuality lens is to get the government to come out with such a policy—where patients have the right to privacy, where they can have space for self-pleasure if they want, for example.

Given the status of sexual and reproductive health of people with psychosocial disabilities, what are some of your recommendations?

Even if we are working with the recovery care model (which espouses that people exercise choices), we need to talk about the sexuality of people with psychosocial disabilities. We can’t just choose to talk about housing, livelihood, to be symptom-free, and not talk about relationships, intimacy, romance, and pleasure. That’s totally contradictory.

The UN should commit to enabling better access to information and knowledge on the interlinkages of sexuality and sexual and reproductive health and rights with mental health and psychosocial disability, and support the building capacity of disability and mental health organisations on these. Even the UN Convention on the Rights of Persons with Disabilities (UNCPRD) only talks about sexuality in the framework of marriage and family. It’s therefore up to us civil society to bring this issue to the forefront for the UN to act upon.

What makes you passionate about this work? Who are or what is your inspiration?

I have witnessed mental health issues from very, very close quarters. Two of my aunts were diagnosed with schizophrenia and were locked away from public gaze in institutions. I also grew up in an extremely liberal family committed to social work. I have always interacted with so-called marginalised people; my best friends were from informal settlements.

Any final thoughts?

Let us not invisibilise people who are different from us, who have a history of mental illness. Let us embrace them, and let us live.

Ratnaboli Ray can be contacted at ratnaboli@anjalimhro.org.

Notes & References

1. Find out more about Anjali at <http://www.anjalimentalhealth.org/founder.php>.
2. While intellectual disability and psychosocial disability may be two different things, sometimes they get confused with each other. Intellectual disability is a condition related to a person’s mental abilities not being developed. On the other hand, psychosocial disability has to do with mental illness. You will never see a child born with a psychosocial disability; it is something that occurs through the life cycle; it is something that we have socially constructed. On the other hand, people are born with intellectual problems.
3. Read more about the Banyan here: <http://www.thebanyan.org/>.
4. Read more about Sangath here: <http://www.sangath.in/>.

ADDRESSING THE SEXUAL AND REPRODUCTIVE HEALTH NEEDS OF YOUNG PEOPLE WITH DISABILITIES IN NEPAL

By Amit Timilsina

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Sexual and reproductive health and rights (SRHR) is still largely a taboo topic in Nepalese culture. Young people have inadequate information and knowledge about the subject and lack access to SRHR services. This is especially challenging for young people with disabilities, whose needs are generally overlooked.¹ A cross-sectional study on young people with disabilities showed that only 38% of the respondents perceived the nearest health service centre to be disability friendly. Provision of physical facilities like ramps, railings, elevators, and suitable toilets were the aspects most mentioned as requirements for a service centre to be called disability friendly. The research also highlights the need to provide information to young people living with disability to make more informed decisions related to their sexual and reproductive health.²

To identify the needs of youth with disabilities, YUWA, Nepal's youth-led organization, conducted focus group discussions with young people living with disabilities. Participants highlighted that disability-related projects and programmes in Nepal are specially targeted to improve people's education and economic situations, but health needs and information related to SRHR and mental health are often neglected. They also emphasized the need for SRHR-related information on family planning, safe sex, menstrual hygiene management, bodily changes, youth-friendly health services, violence, and relationships. Moreover, they flagged that loneliness, rejection, discrimination, abuse, sexual

harassment, and limited information related to SRHR, leads to mental tension, sometimes resulting in depression.

Increasing awareness on SRHR is the foremost step, and thus YUWA has been conducting various initiatives and activities related to SRHR to raise awareness among youth with disabilities. For example, YUWA conducted a one-day workshop on HIV and AIDS for students of the Central Higher Secondary School for the Deaf in Kathmandu as research has highlighted that people living with disability were at increased exposure risk to HIV infection. The students were keen to learn about family planning methods, sexually transmitted infections, including HIV and AIDS, and their associated myths and misconceptions. The discussions addressed various queries raised about HIV AIDS such as whether the virus could be transmitted through mosquitos, by sharing shaving blades, and by kissing, and whether contraceptive methods could prevent transmission. Participants' feedback helped us to broaden our learning, linking disability with other aspects of SRHR such as gender and sexuality, gender-based violence, menstruation, and family planning methods.

YUWA is now collaborating with several disability organizations to impart information related to sexuality and SRHR, and various aspects of SRHR such as menstrual hygiene management, family planning, bodily change, and youth-friendly health services and relationships.

Participants highlighted that disability-related projects and programmes in Nepal are specially targeted to improve people's education and economic situations, but health needs and information related to SRHR and mental health are often neglected. They also emphasized the need for SRHR-related information on family planning, safe sex, menstrual hygiene management, bodily changes, youth-friendly health services, violence, and relationships.

Disability-related organisations are beginning to emphasize the importance of SRHR-related information to young people. YUWA's collaboration with these organisations has enabled cross learning on the sexual and reproductive health and needs of youth living with disability and raised discussion on the need for disability-friendly and youth-friendly service centres. YUWA is developing a learning module to enable young people living with disability to make better-informed decisions on sexuality and SRHR.

Studies have also found mental health issues to be high among youth living with disabilities. Mental health orientation and information related SRHR was provided to members of the Blind Youth Association of Nepal. The programme discussed different types of mental illness, participants'

perceptions on mental health, and stigma and discrimination associated with mental illness. Safe care activities to reduce mental tension and to enhance quality of life were provided. Thus, YUWA has been trying to address SRHR issues of youth with disability through various activities, but challenges remain. It has also become evident that capacity building of organisations not working in the field of disability, to enable them to work on SRHR issues of youth with disability, is a must.

Sharing information related to sexuality and SRHR with youth with various types of disabilities is important. There is a need for civil society organisations, along with government agencies, to work with young people living with disabilities to realize their SRHR. However, this is a challenge due to limited knowledge and resources.

Government should upgrade policies and foster practices to ensure that health services including SRHR services are disability-friendly. Collaboration among stakeholders, including disability

organisations and supporting partners, will promote access to information and services related to SRHR.

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2. Marie Stopes International, "Sexual and Reproductive Health among Young Persons with Disability in Six Districts of Nepal," 2015.

RAISING AWARENESS ON SRHR FOR PEOPLE WITH DISABILITIES: Towards Inclusion of People with Disabilities in Hanoi, Vietnam

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Sexual and reproductive health and rights (SRHR) is considered a sensitive topic in Vietnam due to cultural beliefs. SRHR of people with disabilities is thus often ignored or disdained in both families and society because of negative attitudes towards people with disabilities. The project "Raising Awareness about SRHR for People with Disabilities,"¹ funded by the Abilis Foundation and run by the Bac Tu Liem Association of People with Disabilities² from October 2014–June 2015, aimed at responding to this gap by providing people with disabilities with two training programmes and an experience exchange programme on Sexual and Reproductive Health and Rights.

Participants were encouraged to share their individual and collective experiences to bring SRHR issues to the table. The sharing revealed that they had never

attended any training on SRHR and nobody, not even their family members, had previously talked to them about these issues. Most participants, both males and females, were very hesitant to join the discussions in the beginning. When engaging in a variety of activities such as role-playing, story telling, quiz games, drawing pictures, and watching video clips, participants gradually relaxed and began participating actively. They gained a better understanding of their bodies and of adolescent development, how to maintain personal hygiene, and the distinction between the concepts of "sex" and "gender."

Significantly, some shared their personal stories in order to help others learn how to avoid unwanted sexual experiences as at least three female participants shared having gone through such experiences.

Some participants also wanted to know the differences between sexual violence and sexual abuse. Many concerns were raised and discussed.

Participants revealed misguided notions such as—the sole function of sexuality is for reproduction and women's bodies are for the consumption of their male partners, and therefore it is a woman's duty to keep her body free of sexually transmitted diseases and infections. These are contrary to concepts around affirmative sexuality and pleasure. This illustrated a lack of knowledge on sexuality education as many expressed their misunderstanding about the concepts of sexuality and sexual orientation.

There is also a gender bias. For example, when discussing using condoms,

most participants agreed that men are responsible for using it and women do not need to know. If anyone showed their expertise on this, others would make jokes at their experience. Thus, some men refused to share their views or experiences. Facilitators had to use some specific cases to encourage participants to think further. What if a man did not have a hand? How does a blind man know the right side of a condom? What are the roles of partners in these cases? When analyzing these cases, participants gradually understood that both men and women should know and support their partners in using contraceptive methods. Some addressed obstacles to different types of disabilities such as those encountered by wheelchair users. Gradually, participants became more comfortable and the discussions opened up.

Acquiring knowledge about SRHR is not too difficult for people with disabilities, but putting it into practice is a big challenge. For instance, it is quite hard for a woman to convince her partner to use condoms. Similarly, men felt very hesitant to actively use condoms because it was said that they were promiscuous. Therefore, raising awareness of people with disabilities toward SRHR is just the beginning of changing behaviour or perceptions around SRHR. In order to make people with disabilities enjoy the full range of human rights, including SRHR, there should be collaboration amongst different stakeholders such as disabled people's organisations, medical centres, and women's unions to advocate on SRHR issues for people with disabilities.

Notes & References

1. The project constituted two trainings, one on knowledge about SRHR for 30 people with disabilities (14 males and 16 females) and the other on sexually-transmitted diseases and how to prevent them, how to have a safe sex, how to avoid sexual abuse. In addition, it included an experience exchange programme on the same issues.
2. Bac Tu Liem Association of People with Disabilities (Bac Tu Liem DPO) is a social organization established in 2014 in the Bac Tu Liem district, Hanoi. Its mission is to raise awareness and contribute to the protection of the legitimate rights and benefits of people with disabilities through advocacy, capacity building, access to social services, vocational training, and organizational development. In Bac Tu Liem district, there are more than 2,400 people with disabilities of whom only 224 are members of the Bac Tu Liem DPO.

Huyen, Thi Do. "Women with Mobility Disabilities and Marriage in Hanoi, Vietnam: Exploring the Obstacles." (M.A. paper, Clark University, 2013).

ADDRESSING SRHR CONCERNS FACED BY PERSONS WITH DISABILITIES IN PAKISTAN

In Pakistan, in the absence of a regular census, it is estimated that the total population of people with disabilities is 5.035 million.¹ The current annual growth rate of disabilities is at 2.65%, more than the annual growth rate (2.03%) of the total population of Pakistan.² Only 14% of people with disabilities are employed, with the remaining reliant on family members for financial support.³

Sexual and reproductive health and rights (SRHR) is an important pillar of the human rights framework and the below average results in this area is a poor reflector on the general human rights situation in Pakistan.

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Women with disabilities face inequalities in every field of life. They tend to be more disadvantaged than men with disabilities because of "double discrimination," of being disabled, and being a woman.⁴ This becomes "triple discrimination" when combined with economic status.⁵

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One of the most common problems faced by people with disabilities and especially women with disabilities is the lack of access to comprehensive sexuality education. There is general shyness when it comes to talking about SRHR because cultural norms have deemed it a taboo subject, consequently restricting people's choices on SRHR issues. It is difficult for girls and women with disabilities to exercise autonomy when it comes to making informed decisions about their own bodies and to negotiate safer sex.

They are prone to high risks of unwanted pregnancies and abortions and are victims of exploitation, sexual violence, prostitution, discrimination, and other crises. Women with disabilities have high unmet needs and demands for their sexual and reproductive health; they lack awareness on contraceptives, abortion rights, STIs and STDs, adolescents' health, and reproductive rights.

NFWWD strengthens legal access to a judicial system for affected women, girls, and boys. It also advocates for SRHR in policy negotiations with the Women Parliament Caucus (WPC) as a particular area of focus within the framework of efforts to promote coherence in combating oppression and promoting democracy, human rights, and development.

The National Forum for Women with Disabilities (NFWWD)⁶ is an organisation in Pakistan working to give women with disabilities a leadership platform. NFWWD educates women about their sexual and reproductive rights, including abortion, and a healthy and pleasurable sex life. It provides information and counselling about sexual and reproductive health, including adolescent development and youth SRH issues. It also provides family planning services, and services for those who experience sexual, physical or emotional violence. Additionally, it trains women with disabilities to become peer educators for women who have disabilities and who do not have disabilities in their community, and carries out special campaigns to combat sexual violence and support healthcare, including psychosocial care. NFWWD strengthens legal access to a judicial system for affected women, girls, and boys. It also

advocates for SRHR in policy negotiations with the Women Parliament Caucus (WPC) as a particular area of focus within the framework of efforts to promote coherence in combating oppression and promoting democracy, human rights, and development.

Another organization working to create SRHR awareness among people with disabilities is Visionary Foundation Pakistan (VFP), a youth-led organization working in Pakistan. To date, VFP has organized a conference with blind young people, and three symposiums on SRHR and Disability with more than 300 participants; these events brought together cross-sector academics, NGOs, and activists to debate and address practical policy concerns on a range of SRHR issues including: early marriage; late or no marriages of women with disabilities; lack of relationships between young people with disabilities (boys and girls); stigma attached to marrying a person with a disability; the myth that children of people with disabilities will be born with a disability; and sexual abuse of children (especially girls) with mental health disabilities. The event was organised to ensure participation of parents and stakeholders to share their understanding and concerns related to SRHR of people with disabilities, including sexual and reproductive health issues among women with disabilities.

People with disabilities go through a range of issues every day, including stigma and discrimination. They are discriminated and excluded from social, economic and political decision-making in society. Although the Government of Pakistan ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in July 2011, there are hardly any programmes implemented on SRHR of people with disabilities. However, work done by organizations such as NFWWD and VFP go a long way in sparking new

debates and changing attitudinal mindsets towards people with disabilities in the country.

People with disabilities go through a range of issues every day, including stigma and discrimination. They are discriminated and excluded from social, economic and political decision-making in society. Although the Government of Pakistan ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in July 2011, there are hardly any programmes implemented on SRHR of people with disabilities.

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2. Ibid.
3. Ibid.
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6. <http://www.nfwwd.org/>.

RESOURCES FROM THE ARROW SRHR KNOWLEDGE SHARING CENTRE

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ARROW's SRHR Knowledge Sharing Centre (ASK-us) hosts a special collection of resources on gender, women's rights, and sexual and reproductive health and rights (SRHR). It aims to make critical information on these topics accessible to all. The ARROW ASK-us will be going online in the last quarter of 2017. To contact ASK-us, write to km@arrow.org.my.

WOMEN WITH DISABILITIES – DISABLED, SEXUAL, AND REPRODUCTIVE

Frohman, Carolyn and Stephanie Ortoleva. *The Sexual and Reproductive Rights of Women and Girls with Disabilities*. Issues paper. ICPD Beyond 2014 – International Conference on Human Rights, July 1, 2013. http://wwda.org.au/wp-content/uploads/2013/12/issues_paper_srr_women_and_girls_with_disabilities_final.pdf.

This paper examines the sexual and reproductive rights of women and girls with disabilities in the context of the future development agenda Beyond 2014 and Post 2015. It focuses on women and girls with disabilities, recognising that they are generally more likely to experience infringements of their sexual and reproductive rights. It examines some of the key sexual and reproductive rights violations experienced by women and girls with disabilities around the world.

Graduate Journal of Social Science (GJSS). *Sexualities and Disabilities*. GJSS, 12:1 (2016). Accessed August 21, 2017. <http://gjss.org/sites/default/files/issues/full/GJSS%20Vol%2012-1.pdf>.

The special issue on “sexualities and disabilities” of this peer-reviewed interdisciplinary journal presents and addresses the under-represented and marginalised voices of people with disabilities and their sexuality. Papers in

this special issue cover a wide range of topics including people disabled during war, mental disability, caregivers of soldiers disabled in war, representation of disability in art and culture, and juxtaposition of issues of people with disabilities with other marginalised communities such as people of diverse genders and sexualities.

Greenwood, Nechama W. and Joanne Wilkinson. “Sexual and Reproductive Health Care for Women with Intellectual Disabilities: A Primary Care Perspective.” *International Journal of Family Medicine*, 2013:642472 (2013). doi:10.1155/2013/642472. <https://www.hindawi.com/journals/ijfm/2013/642472/>.

This paper is based on a limited literature review related to six aspects of sexual healthcare of women with intellectual disabilities, including barriers to sexual healthcare, sexuality education, sexual abuse and consensual sexuality, contraception, screening for sexually transmitted infections and cervical cancer, and pregnancy and parenting. Besides providing background information on each of these topics, practice recommendations are made for primary care clinicians, using a rights-based framework.

Maurya, Abha Khetarpal. “Why it’s vital for young people with disabilities to receive sex education.” Blog post. *Sexuality and Disability*, July 25, 2017.

Accessed July 25, 2017. <http://blog.sexualityanddisability.org/2017/07/sexed/>.

As a counsellor for persons with disabilities and a disability rights activist, the author shares insights on the needs for young people with disabilities to receive sexuality education. She highlights that sexuality education would enhance the lives of young people with disabilities in terms of information, attitudes, values, relationships, and their interpersonal skills.

Naphtali, Kate and Edith Machattie. *PleasureABLE: sexual device manual for persons with disabilities*. Disabilities Health Research Network, 2009. http://www.dhrn.ca/files/sexualhealthmanual_lowres_2010_0208.pdf.

This manual is a practical resource for persons with disabilities and healthcare clinicians who work with these clients. It includes research, clinical expertise, and product information to aid with dialogue surrounding sexual and reproductive issues and disabilities. It provides examples and illustrations of potential options that can be introduced into the sexual practices of the individual.

Reproductive Health Matters (RHM). *Disability and sexuality: claiming sexual and reproductive rights*. RHM, 25:50 (2017). <http://explore.tandfonline.com/content/med/zrhm-disability-and-sexuality-special-issue>.

resources

This themed issue on disability and sexuality brings together a selection of articles that sheds light on the population of people with disabilities, focusing on their sexual and reproductive health and rights. Among the topics covered include access to family planning and sexual and reproductive health services, parenthood, sexual rights of the disabled, and female genital mutilation as sexual disability.

Sexual and Disability. Point of View (POV) Blogs. <http://www.sexualityanddisability.org/>.

sexualityanddisability.org is a website providing information to questions a woman with a disability might have—about her body, about the mechanics and dynamics of having sex, about the complexities of being in an intimate relationship or having children, about unvoiced fears or experiences of encountering abuse in some form.

Silvers, Anita PhD, Leslie Francis, JD, PhD, and Brittany Badesch. “Reproductive Rights and Access to Reproductive Services for Women with Disabilities.” *American Medical Association Journal of Ethics*, 18:4 (2016): 430-437. Accessed May 25, 2017. doi:10.1001/journalofethics.2016.18.04.msoc1-1604. <http://journalofethics.ama-assn.org/2016/04/msoc1-1604.html>.

This article explores whether women with disabilities have equitable access to reproductive health services, including family planning, contraception, screening for sexually transmitted infections, maternal health services, and fertility services. It highlights that mistaken assumptions on women with disabilities with regard to SRHR can lead to misjudgements in the provision of reproductive care for women with disabilities.

TARSHI. “The Editorial: Disability and Sexuality.” *In Plainspeak*, August 2017. <http://www.tarshi.net/inplainspeak/editorial-9/>.

The key question of whether persons with disability can have or should have sex are rooted in the assumption that they lack the ability, competence, appropriateness etc., to do so. This is largely due to the perceptions of the world that are constructed to exclude them. However, efforts are made daily to build on valuing the diversity of experiences of persons with disability. Plainspeak’s August issue articulates these complexities in realising the ideals of equal opportunity on the issues pertaining to accessibility and sexuality.

World Health Organisation (WHO) and United Nations Population Fund (UNFPA). *Promoting sexual and reproductive health for persons with disabilities.* WHO/UNFPA Guidance Note. WHO and UNFPA, 2009. https://www.unfpa.org/sites/default/files/pub-pdf/srh_for_disabilities.pdf.

This guidance note addresses issues of sexual and reproductive health (SRH) programming for persons with disabilities. It is intended for SRH experts and advocates within UNFPA and WHO as well as those in other development organizations and partners. Those who address issues of family planning, maternal health, HIV and AIDS, adolescents, and gender-based violence (GBV) may find this information particularly helpful. SRH, in particular, deserves attention because these needs have been so widely and so deeply neglected. At the same time, the approaches discussed apply broadly to all aspects of health programming for persons with disabilities.

United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP). *Incheon Strategy to “Make the Right Real” for Persons with Disabilities in Asia and the Pacific.* Bangkok: UN Publications, 2012. <http://www.unescap.org/sites/default/files/Incheon%20Strategy%20%28English%29.pdf>.

The Incheon Strategy builds on the Convention on the Rights of Persons with Disabilities and the Biwako Millennium Framework for Action and Biwako Plus Five towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific. This strategy will enable the Asia 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.

LIST OF FILMS

ACCSEX is a 2013 film directed by Shweta Ghosh that explores notions of beauty, the “ideal body” and sexuality through four storytellers; four women who happen to be persons with disability. More on the film at <http://www.filmsouthasia.org/film/accsex/> and <https://www.youtube.com/watch?v=nkh7gS9e7s8>.

Dance Me to My Song, a 1998 Australian drama of a profoundly moving love triangle involving a woman with cerebral palsy, her abusive caretaker, and a young male companion. More on the film at https://en.wikipedia.org/wiki/Dance_Me_to_My_Song and <https://www.youtube.com/watch?v=tHILQNrHxQ>.

Margarita with a Straw, a 2014 film featuring a rebellious young woman with cerebral palsy, leaving her home in India to study in New York, who unexpectedly falls in love, and embarks on an exhilarating journey of self-discovery. More on the film at https://en.wikipedia.org/wiki/Margarita_with_a_Straw and <https://fmovies.is/film/margarita-with-a-straw.kw7p9/wnwkj7>.

Scarlet Road, a 2011 documentary follows the extraordinary work of an Australian sex worker, Rachel Wotton, who sells sex to clients with disability. More at https://en.wikipedia.org/wiki/Scarlet_Road and https://www.youtube.com/watch?v=DMXjc_Ow4mg.

Sixth Happiness is a 1997 film about Brit, a boy born with brittle bones, who does not grow taller than four feet, and his sexual awakening as family life crumbles around him. More at https://en.wikipedia.org/wiki/Sixth_Happiness and <http://player.bfi.org.uk/film/watch-sixth-happiness-1997/>.

The Sessions, a 2012 film on a man on an iron lung who wishes to lose his virginity, and contacts a professional sex surrogate with the help of his therapist and priest. More at [https://en.wikipedia.org/wiki/The_Sessions_\(film\)](https://en.wikipedia.org/wiki/The_Sessions_(film)) and <https://fmovies.is/film/the-sessions.v882/r4x790>.

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ARROW RESOURCES

All ARROW publications from 1993 to the present can be downloaded at <http://arrow.org.my/publications-overview/>.

DEFINITIONS

Accessibility: “Accessibility describes the degree to which an environment, service, or product allows access by as many people as possible, in particular people with disabilities.”¹ Article 9 of the United Nations (UN) Convention on the Rights of Persons with Disabilities requires countries to adopt measures “... to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.”

Disability: “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.”² Article 1 of the UN Convention on the Rights of Persons with Disabilities defines persons with disabilities as including: “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.”

Psychosocial Disability: “Psychosocial disability is an internationally recognised term under the United Nations Convention on the Rights of Persons with Disabilities, used to describe the experience of people with impairments and participation restrictions related to mental health conditions. These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives. Psychosocial disability relates to the “social consequences of disability”—the

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effects on someone’s ability to participate fully in life as a result of mental ill-health. Those affected are prevented from engaging in opportunities such as education, training, cultural activities, and achieving their goals and aspirations. Not everyone with a mental illness will have a level of impairment that will result in a psychosocial disability.”³

Reproductive Health: “A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the

right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant.”⁴

Reproductive Rights: “[E]mbrace certain human rights that are already recognized in national laws, international human rights documents, and other consensus documents. These rights rest on the recognition of the basic right 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 their right to make decisions concerning reproduction free of discrimination, coercion, and violence, as expressed in human right documents.”⁵

Sexual Health: “A state of physical, emotional, mental and social well-being 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.”⁶

Sexual Rights: “[E]mbrace human rights that are already recognised in national laws, international human rights documents, and other consensus

documents. They include the rights of all persons, free of coercion, discrimination, and violence, to the highest attainable standard of health in relation to sexuality, including access to sexual and reproductive health care services; seek, receive, and impart information in relation 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.”⁷

Sexuality: “Sexual health cannot be defined, understood or made operational without a broad consideration of sexuality, which underlies important behaviours and outcomes related to sexual health. The working definition of sexuality is: . . . a central aspect of being human throughout life 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, legal, historical, religious and spiritual factors.”⁸

definitions

Notes & References

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3. Extracted from Mental Health Council of Australia (MHCA) website: <https://mhaustralia.org/general/getting-ndis-right-people-psychosocial-disability>.
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5. United Nations, “Programme of Action,” para 7.3.
6. This is a working definition, not an official WHO position. See: World Health Organisation, “Sexual and Reproductive Health,” http://www.who.int/reproductivehealth/topics/gender_rights/sexual_health/en/.
7. Ibid.
8. Extracted from the World Health Organisation (WHO) website: http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/.

RELUCTANCE OR IGNORANCE: Ensuring SRHR of Women with Disabilities in Legislation

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The Convention on the Rights of Persons with Disabilities (CRPD), the treaty on the rights of persons with disabilities, guides States on laws and policies addressing discrimination against people with disabilities, using a rights-based approach. CRPD adopts a social disability model, moving away from approaching people with disabilities as incapable and in need of protection and/or correction, and looks at ways of removing barriers that restrict their life choices.

CRPD recognises that women with disabilities¹ are subject to multiple discrimination, and obligates States to take appropriate measures to address multiple and intersecting forms of discrimination. This was further expanded by the Committee on the Rights of Persons with Disabilities (Committee) in its General Comment² ³ that discrimination is not experienced by people as members of a homogenous group but, rather, as individuals with multidimensional layers of identities, status and life circumstances. The general comment specifically recognizes the denial of sexual and reproductive health and rights (SRHR) of women and girls due to stereotypes based on disability and gender as a form of discrimination. Harmful stereotypes of women with disabilities include the belief that they are asexual, incapable, irrational, lacking control, and/or hypersexual. The General Comment therefore emphasizes that women with disabilities have the right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination, and violence.

CRPD adopts a social disability model, moving away from approaching people with disabilities as incapable and in need of protection and/or correction, and looks at ways of removing barriers that restrict their life choices.

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) also recognizes the role of stereotypes in the denial of human rights towards women with disabilities. More specifically, the CEDAW Committee, in General Recommendation 18,⁴ requested States to specifically report on measures taken to eliminate discrimination against women with disabilities.

CRPD and CEDAW: Has it Shaped Laws and Policies for Women with Disabilities? The ratification of CRPD and CEDAW has led to a revision in laws and policies for the development of people with disabilities, but has not brought about a real change in the laws and policies around disability in many countries, particularly with regard to the specific discrimination faced by women with disabilities. However, these revisions often have a gender-neutral approach towards disability, prioritizing issues of access, education, and employment, rendering the specific concerns of women with disabilities, especially with regard to their SRHR, invisible. The “gender-mainstreaming, disability-inclusive” approach draws upon a feminist-disability discourse that seeks to challenge dominant assumptions about

living with a disability, and it situates the disability experience in the context of rights and exclusions. It also questions the assumption that disability is a flaw or a deficiency. In order to do so, it defines disability broadly from a social rather than a medical perspective.⁵ Hence, participation and inclusion of people with disabilities emphasizes on looking at the social and physical barriers for such participation and addressing these barriers and concerns. This approach also necessitates addressing stereotypes related to gender and sexuality which form a significant social barrier for women with disabilities.

The “gender-mainstreaming, disability-inclusive” approach draws upon a feminist-disability discourse that seeks to challenge dominant assumptions about living with a disability, and it situates the disability experience in the context of rights and exclusions. It also questions the assumption that disability is a flaw or a deficiency. In order to do so, it defines disability broadly from a social rather than a medical perspective.

Malaysia ratified CEDAW and CRPD in 1995 and 2010 respectively. The National Welfare Policy of Malaysia (2017–2020) has come under severe criticisms from the disability rights movement because it views people with disabilities as impaired and in need of correction.

This approach tends to treat them as dependents, always in need of “support” which society will give as and when it chooses.⁶ Similarly, Indonesia⁷ has adopted a number of laws and policies on disabilities, most of which are based on a charity model.⁸ In 2016, Indonesia passed a new legislation⁹ ostensibly adopting a rights-based approach; however, the reports and data collection around disabilities hardly addressed the question of women’s SRHR. For instance, a study¹⁰ looking at issues of disability in Indonesia by the Demographic Institute does not address issues around SRHR at all. Similarly, Bangladesh, which ratified the CRPD in 2007, passed the Rights of Persons with Disabilities Act, 2013, which takes a rights-based approach towards disability, based on CRPD.¹¹ However, the law does not address key issues around SRHR and the specific rights of women with disabilities. Likewise, the National Policy of Persons with Disabilities Act, 2002,¹² of Pakistan adopts a charity and welfare model towards people with disabilities. Two of the countries in the region, Sri Lanka and Democratic Republic of Korea, ratified the CRPD only in 2016; the process of revision of legislation is under way and it is essential that this draft law specifically addresses the rights of women with disabilities. India passed a law on the Rights of Persons with Disabilities in 2016, after a long struggle by the disability rights movement and activists. The law goes far in addressing issues of the rights of people with disabilities, acknowledging that the law should recognize the legal capacity of people with disabilities, and mentions the specific needs of women with disabilities.¹³

This neglect of SRHR of women with disabilities in laws and policies is a common phenomenon across many countries in the Asia-Pacific region. A study¹⁴ looking at Indonesia, Laos and Vietnam has highlighted that laws and

policies are not sufficient legal protection for women with disabilities. The study also highlighted that healthcare implementers are often unaware of ways to deal with disability; laws often do not cover the specific needs of women with disabilities, and women with disabilities are also often unaware of existing legal protections. Women with disabilities who choose to have a child are often criticized for their decision and face barriers in accessing adequate healthcare and other services for themselves and their children. This neglect towards the specific needs of women with disabilities is prevalent within the Committee as well, where sexuality and SRHR of women with disabilities is addressed through a protectionist approach rather than as a right.¹⁵

Women with disabilities who choose to have a child are often criticized for their decision and face barriers in accessing adequate healthcare and other services for themselves and their children.

Conclusion. In November 2012, The Asia-Pacific governments at the High-level Intergovernmental Meeting adopted the Ministerial Declaration on the Asian and Pacific Decade of Persons with Disabilities 2013–2022 and the Incheon Strategy¹⁶ to “Make the Right Real” for people with disabilities in Asia and the Pacific. It provides the first set of regionally agreed disability-inclusive development goals. The Incheon Strategy is designed to help the Asia and Pacific region to track progress towards improving the quality of life, and the fulfilment of rights, of people with disabilities. Progress in the implementation of the Ministerial Declaration and the Incheon Strategy will be monitored every three years by the

factfile

Progress in the implementation of the Ministerial Declaration and the Incheon Strategy will be monitored every three years by the secretariat of the Economic and Social Commission of Asia and the Pacific. The strategy has 10 goals, with targets under each goal, including reducing poverty, education access, and employment. Goal 6 ensures gender equality and women’s empowerment and a specific target under the goal is equal access to sexual and reproductive health services.

secretariat of the Economic and Social Commission of Asia and the Pacific. The strategy has 10 goals, with targets under each goal, including reducing poverty, education access, and employment. Goal 6 ensures gender equality and women’s empowerment and a specific target under the goal is equal access to sexual and reproductive health services. Furthermore, the adoption of sustainable development goals in 2015, with the core principle of leaving no one behind, provides an opportunity to push governments to address these issues. Particularly, Goals 3 and 5, ensuring healthy lives and well-being and gender equality, should be read together with every country’s human rights commitments including CEDAW and the CRPD. All of these provide activists and organisations working on disabilities the opportunity to push for better laws, policies and implementation in every country—and opportunities to ensure that the specific issues and concerns of women with disabilities are heard.

COUNTRY/REGION	RATIFICATION/ ACCESSION OF CRPD	RATIFICATION/ ACCESSION OF CEDAW
Bangladesh	2007	1984
Cambodia	2012	1992
China	2008	1980
India	2007	1993
Indonesia	Signed 2010, not ratified	1984
Lao People's Democratic Republic	2009	1981
Malaysia	2010	1995
Maldives	2010	1993
Mongolia	2010	1981
Myanmar	2011	2011
Nepal	2010	1991
Pakistan	2011	1996
Philippines	2008	1981
Singapore	2013	1995
Sri Lanka	2016	1981
Thailand	2008	1985
Timor Leste	No	2003
Viet Nam	2015	1982

Notes & References

- Article 6 of CRPD deals with discrimination of women and girls with disabilities.
- General Comments are recommendations by the Committee on issues in the Convention that they think the States should focus on in their report or description of the articles in more detail.
- http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/3&Lang=en.
- <https://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm#recom18>.
- Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/35/21 available at <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/076/04/PDF/G1707604.pdf?OpenElement>.
- M. Rezaul Islam, "Rights of Persons with Disabilities and Social Exclusion in Malaysia," *International Journal of Social Science and Humanity*, 5:2 (2017), available at <http://www.ijssh.org/papers/447-H10019.pdf>.
- Indonesia is yet to ratify CRPD.
- International Labour Organisation, "Inclusion of People with Disabilities in Indonesia," available at http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---ilo-jakarta/documents/publication/wcms_233427.pdf.
- A transcript of the law is unavailable and hence the author cannot comment on it.
- <http://www.tnp2k.go.id/images/uploads/downloads/Disabilities%20report%20Final%20sept2014%20%281%29.pdf>, accessed on September 15, 2017.
- https://www.apcdfoundation.org/?q=system/files/Persons%20with%20Disabilities%20Rights%20and%20Protection%20Act%202013_o.pdf, accessed on September 15, 2017.
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- <http://www.unescap.org/sites/default/files/Incheon%20Strategy%20%28English%29.pdf>.

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"Looking at the World Through a Friend."

I haven't found where I belong. And never will.

It is okay. At least I know where I don't belong.

- The Schizophrenist -

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