Submission by CREA, Anjali and Point of View to the Report of the Special Rapporteur on the rights of persons with disabilities on sexual and reproductive health and rights of girls with disabilities

People with disabilities are inhibited from realizing their full human rights by multiple physical and attitudinal barriers. Women with disabilities often face multiple forms of discriminations, based on race, class, socio economic status, gender and age, due to restrictions imposed by social norms inherent to these aspects of their identities or gender expression. It is not possible to effectively work to advance the rights of women with disability without also understanding and addressing issues related to sexuality, sexual and reproductive health gender and rights, and recognising the cultural, social and legal norms that deeply influence them.

Since early 2015, a collaborative process emerged between CREA (Delhi, India), Anjali (Kolkata, India), Equals (Chennai, India), Point of View (Mumbai, India) and Sruti Disability Rights Center (Kolkata, India) to work jointly to build understanding, capacity and create visibility about issues related to sexuality and disability rights. Through this collaboration, activists and organisations working on disability rights, women's rights, sexuality and SRHR have come together to facilitate capacity building of Disabled People’s Organisations and women and girls with disabilities. The submission that follows has emerged from the work that has been jointly undertaken by different members of this collaboration. However, this submission before the Special Rapporteur is on behalf of CREA, Anjali and Point of View only.

# About CREA

CREA is a feminist human rights organisation based in New Delhi, India, working with partners (in India, Nepal and Kenya) from a diverse range of human rights movements and networks, to advance the rights of women and girls, and the sexual and reproductive freedoms of all people. To advance its goals, CREA uses an intersectional approach in all of its work, including work on disability and sexuality, through capacity building and direct advocacy and lobbying. CREA's work on sexuality and disability addresses misconceptions and prejudices about disabled women's sexuality and sexual and reproductive health and rights (SRHR). It seeks to provide women with disability information, change public perception on these issues and influence laws and policies to be more inclusive of disabled women's rights.

# About Anjali, Mental Health Rights Organisation

Anjali, set up in 2001, is a voluntary organisation, working in the field of mental health in cross-sectoral partnerships with the Dept of Health and Family Welfare, Government of West Bengal, Panchayat and Municipalities of West Bengal. The organisation designs and implements programmes keeping the person with mental health conditions or psycho social disability at the centre. The organisation also work with other NOGs/CSOs, network, media and civil society at large to strive to shape the field of mental health and human rights in India.

**About Point of View**

Point of View is a Mumbai- based non profit organisation established in 1996. It amplifies women’s voices and removes barriers to voice, speech and expression. Through media, education, technology, and art, Point of View works at the intersection of gender, sexuality and violence. At its sexuality and disability program, Point of View believes that girls and women with disabilities are sexual beings just like anyone else. Love, Sex, Romance, Intimacy, Having children, dealing with the ins and outs of relationships, these are all everyday aspects of sexuality. But women with disabilities are often cut off from these life experiences, mainly because they’re seen as asexual. Point of View empowers women with disabilities by helping them change their ideas of themselves. Point of View’s pioneering site, sexualityanddisability.org, provides information on everything from body image and menstruation to sexual harassment and abuse. Their flagship workshops do the same - on the ground.

# Sexual and Reproductive health and rights of women and girls with disability

While it is greatly appreciated that the Special Rapporteur is addressing sexual and reproductive health and rights, it is vital to expand on the same to include not just girls but women as well. Sexual and reproductive health and rights is the most under-addressed area of rights when it comes to persons with disability. In such a scenario to further reduce the narrative and exclude the intersectionality in the sexual and reproductive health and rights of women and girls would risk the attainment of such rights.

In order to understand the work of disability rights organisations and to gauge and document their knowledge, access to information about body, bodily changes, relationships, sexuality, violence and how they might be addressing these issues, a Needs Assessment was conducted in 2015. As part of the needs assessment survey 27 Disabled people’s organisations and women’s rights organisations and activists in India were interviewed and two facilitated group discussions with 20 women living with psychosocial disabilities were conducted. Along with this, interviews and FGDs were conducted with 41 young women with disabilities associated with National Association of Blind, Delhi and The Leprosy Mission Trust, Delhi.

In this submission we would like to share some of the findings of the needs assessment to further emphasise on the importance of addressing sexual and reproductive health and rights of women and girls.

1. **Misconceptions and Ideas around Sexuality and Reproductive Health**

The needs assessment highlighted that the Disabled People’s Organisations themselves did not have a comprehensive understanding on gender or sexuality. Yet, they themselves articulated the importance of trainings on issues of sexual and reproductive health and rights. A few quotes below provide a glimpse into lack of understanding on sexuality, gender and rights that some organisations might have:

* “For pwd male or female problems are the same. Girls with disabilities of course we need to keep more restrictions on time and all.”
* “And when boys are sexually abused, they become homosexuals. However the parents do not want that boys will be taught about sexual abuse.”
* “Human beings have not degraded so much that they will harass or abuse the blind woman. In thirteen years we haven’t heard a single case.”
* “There are a bit of homosexual tendencies. I tried to separate them. From their body language and attitude I could make out. Percentage is very less. So forcibly I sent the girls home.”
* “We should have a standard for whether a person is fit for marriage.”
1. **Definite Need for Information around Sexual and Reproductive Health**

In the survey, the respondents were asked if talking about sexuality and reproductive health and rights are important for persons with disability. Most respondents said it was very important since people with disability are usually seen as asexual or without any desire. Information around sexual and reproductive health and rights is important in helping women and girls distinguishing between good touch and bad touch and also provides them with adequate information before entering into relationships. The respondents also mentioned that giving such information in school settings is very challenging and that parents of disabled children fear the natural process of sexuality, as they aren’t sure how to communicate with their children about such needs.

A concern that was expressed by the respondents was on what and how much information should be provided and more importantly the need to provide information and capacity building to not just the girl or woman with disability but all the stakeholders. One respondent articulated this by saying, “*If that person wants to marry, or have a relationship or wants to masturbate.... how we are responsible and how they are responsible....both sides need to be articulated. It is not that I am a spokesperson for her needs. I am listening yes. But we should also be able to provide a space to address what she can do with her needs. Should we decide that? Or should the individual decide, in connection with the component of responsibility that I mentioned earlier? This is something that needs to be thought about*.”

1. **Building Capacity on Sexual and Reproductive Health and Rights**

Through this collaboration, trainings were conducted with disabled people’s organisations’ (DPOs) staff, men and women with disabilities, including young women with disabilities, teachers, special educators and parents and women’s and gender rights activists in Maharashtra, Tamil Nadu and West Bengal. Through these trainings, we were able to reach persons with a wide range of disabilities- visual disability, hearing and speech disability, loco-motor disability, women living with psycho social disability. We also designed trainings to influence the ecosystem of persons with disabilities, and conducted trainings with teachers, special educators parents as well as staff of DPOs. The overall idea was also to build a cross-movement understanding of the Sexual and Reproductive Health issues, needs and rights of women and girls with disabilities and hence some of the trainings also had participants who are trans\* activists, women’s rights activists, lawyers, academics etc.

The trainings were conducted with a view to encourage disability rights organisations to acknowledge sexual rights as an important aspect for women with disabilities and to introduce women with disabilities themselves to everyday aspects of sexuality, of being sexual, leading sexual lives, having sexual selves, orientations, identities and pleasure. The trainings also sought to introduce complex issues of sexual expressions to special educators and parents of disabled children and encourage disability rights, women and gender rights activists and organisations to acknowledge sexual rights as an important aspect for women with disabilities.

The following themes have been central to all the trainings:

• Understanding body, body image, self esteem

• Myth busting about sexuality

• Sex education and reproductive system

• Consent and choice

• Sexual desires, sexual orientation and sexual pleasure

• Socializing, dating, marriage, relationships

• Abortion rights, sexually transmitted diseases and HIV

The training program was conducted by sets of facilitators most suited for the training – disability rights activists, women’s rights activists including women with disabilities themselves. Some of the partners also included gynaecologists and counsellors for some parts of the training. Some of the training included tactile body models for sessions on understanding bodies and hands-on condom usage training. The trainings also made use of film montage comprising of various romantic and sensual songs, both in Hindi and Bengali. Other trainings used case studies about experiences of people with disabilities, including women and children. Some trainings addressed issues of violence on disabled women, while others intentionally aimed at probing into the positives and the unspoken within the realm of sexuality and disability.

The trainings offered many crucial learning in terms of methodologies for all partners. At the start of the work the trainings were envisioned as one day long trainings covering the various sessions. However, over a course of a number of trainings, it was seen that a longer format is better suited for trainings since, rapport building amongst the participants is crucial for the trainings to be effective. The longer format also provided sufficient time to address various issues and concerns that arise on account of disability such as motivation and self-esteem. It had emerged from the trainings that addressing these concerns was necessary before proceeding to discussions around gender and sexuality. One of the crucial learnings in terms of methodologies was also in understanding how to accommodate accessibility needs of different disabilities when designing methodologies. For example, sufficient time needs to be provided for information to be translated into sign language. Some of the partners also grappled with ways to pitch the trainings and workshops to different groups. From calling it sexuality training to body and special training, the partners had to make various calls on the best way to find an entry point to initiate conversations around sexuality.

The trainings using different mediums also raised many interesting questions around the language employed in talking about gender and sexuality. It was felt that the use of language to talk about sexual and reproductive health created a conundrum wherein on one hand use of overly academic language to refer to sexual and reproductive parts made the concepts abstract and unrelatable, while on the other the use of the local/slang words affected the respectability with which one viewed sex. Similarly, a lot of gaps could be identified in the use of sign language as many words such as violence have no equivalent expression in sign language. It could also be seen that the sign language interpreters often act as gatekeepers and the meaning may not be fully conveyed if the information is not in consonance with the interpreters value and belief system. Training of interpreters, was therefore, identified as a crucial area of intervention, so as to make the trainings and workshops more effective and efficient.