Understanding Sexual Health and Rights of Youth with Disabilities in Assam - A Study

2015-2016

Prepared by
Foundation For Social Transformation
enabling north east india
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FOREWORD

It is indeed a sad anomaly that as India moves into the 21st century with hopes of emerging as a global leader, the very idea of talking about "sex" still remains a taboo. Meanwhile, the incidence of sexual violence has been steeply rising, as have been discussions about what can be done to curb it. Although in the aftermath of the tragic Delhi rape case of 2012, society is now far less tolerant towards sexual violence and some progressive steps have been taken in amending the CrPC, e.g. Justice Verma Commission, which recommends that the gradation of sexual offences should be retained in the Indian Penal Code, 1860 (IPC). Despite such steps, the taboo attached to the act of sex still remains and entrenched biases and misinformation about sexual health, rights, and behaviour are still strong and there is very little space to talk about these matters. When it comes to persons with disabilities their sexual health and need to explore their sexuality is totally ignored, as it is assumed that they have more complex concerns to cope with. As young persons with disabilities do ‘grow up’ / reach puberty and struggle to understand the changes in their body and desires, often indulging in socially unacceptable behaviour, they don’t have any space or opportunity to access whatever little basic sex education which their non-disabled peers have.

Youth Development is a key thematic area at FST and was formalised with the adopting of the Strategy on Fostering Youth Development and Action in 2012. During the many training programs and interactions with young people that were organised by FST in the past, Gayatri Buragohain, erstwhile Executive Director, found that young people were especially keen to talk about issues related to sexuality, sexual health and sexual rights. They had so many questions yet so little space to talk freely about these issues and so few mentors to seek unbiased advice from. While the limited work we did to bust myths around these issues for our young friends was satisfying, it was a matter of concern that we were only able to reach out to a few. In the course of casual conversations that Gayatri had with Arman Ali, Executive Director of Shishu Sarothi (a leading disability rights organisation of Assam), as well as Board Member of FST, our attention was directed to the grim reality of the sexual health and sexual rights related needs of youth with disabilities. Subsequent discussions at Shishu
Sarothi affirmed the sore need for intervention in this area and led to the evolution of the idea of a study that would help us understand the sexual health and sexual rights of youth with disability, in Assam for a start. Conceived as a Knowledge Attitudes and Practices (KAP) study to get some initial understanding of the situation in the community, the plan was to then share the findings with the community and later develop and disseminate a module for training young people with disabilities and their parents, teachers and caregivers to deal with their sexuality and to have better clarity on their sexual health and sexual rights. We were lucky to have found an equally passionate funder for this idea in National Foundation of India (NFI) and the collaboration and support of Shishu Sarothi and other likeminded community based organisations working with people with disabilities, who readily shared their thoughts and views and participated actively in the project. We have reached out to seek technical assistance and advice from experts in sensitively designing questionnaires and conducting focus group discussions. Within FST too our own team worked hard to carry out this groundbreaking study, marked by new learnings and gathering fresh insights along the way.

We feel that this study is a first step towards understanding this vital issue and marks the beginning of a dialogue on sexual health and sexual rights of Youth with Disabilities in Assam that can inform and assist any future interventions in assertion of the rights of youth with disabilities.

Ritupon Gogoi
Executive Director
Foundation for Social Transformation
ACKNOWLEDGEMENTS

Our sincere gratitude goes out to the young people, parents, teachers, special educators and caregivers, who participated in this study. Thank you for letting us into your lives and sharing it with us. This study would not have been possible without you all.

We are beholden to National Foundation for India (NFI), for believing in us and so readily agreeing to support and fund this idea. Special thanks are due to Sathyasree Goswami, Project Director - Youth Innovation Fund, for infusing the project with her enthusiasm and contagious positive energy, as well as providing critical inputs and ideas.

We are grateful to Shishu Sarothi Centre for Rehabilitation and Training for Multiple Disability, Guwahati for being the implementing partner for the project and appreciate all the ground support and technical inputs and advice provided by Arman Ali and the Shishu Sarothi staff team.

We acknowledge the active participation, support and cooperation of our Community Based Organisation (CBO) partners Prerona Pratibandhi Shishu Bikash Kendra (Jorhat), Mrinaljiyoti Rehabilitation Centre (Duliajan), Sanjivani Trust (Tezpur), that made this study possible.

Dr. Arundhati Char (Research Consultant), who mentored and supported us with the research methodology and data collection aspect of this Study, Prabha Nagaraja of ‘Talking about Reproductive and Sexual Health Issues’ (TARSHI), who gave us invaluable critical technical inputs in structuring the report. Bishakha Dutta & Nidhi Goyal of ‘Point of View’, who gave us detailed feedback and constantly reassured us that we were on the right track as we went about the Study.

Thanks are due to all team members and data collectors involved in making this study a reality. The FST team of Kongkana Bordoloi, erstwhile Program Associate and Namrata Goswami, Program Manager & team leader, who has toiled tirelessly on this project.
ACRONYMS & ABBREVIATIONS

ASD - Autism Spectrum Disorder
CP - Cerebral Palsy
DK/CS - Don't Know / Can't say
DM - Deaf and Mute
FST - Foundation for Social Transformation
HI - Hearing Impaired
ID - Intellectual Disability
IDD - Intellectual Development Disorder
KAP - Knowledge Aptitude Practice
MR - Mental Retardation
NE - North East
NFI - National Foundation for India
SHSR - Sexual Health & Sexual Rights
SRH - Sexual and Reproductive Health
VI - Visually Impaired
WHO - World Health Organisation
YwD - Youth with Disability
EXECUTIVE SUMMARY

Sexual health and sexual rights of persons with disability do not seem to be a very important area of discussion or deliberation for most of us in society and this includes parents, teachers, special educators, and caregivers too. The reason for not venturing into this particular area is the mindset and surrounding myths about people with disabilities and the perception that they are not sexual beings. The common belief is that because of their limitations, people with disabilities do not feel the desire to have sex; people with developmental and physical disabilities are seen as childlike and dependent. Another popular myth is that people with disabilities are oversexed and unable to control their sexual urges. However, the reality is that people with disabilities are as human as the rest of us and they have feelings, fantasies and sexual aspirations, like anyone else. They are unable able to express their sexuality fully because of their disability, and more due to restrictions on their mobility, negative societal attitudes towards them and the lack of educational, entertainment, social and health services and rights, that are available to other people. Moreover these issues are also lowest in priority in the current discourse on disability.

In a country like India where rights of people with disabilities are still to be included in public discourse despite existing legislation, and when anything related to the word “sex” is still considered by many as a taboo, sexual health and sexual rights of people with disabilities is a very far cry from the universally inclusive world we would ideally like to see. In North East India, the issue of sexual health and rights is yet to figure in mainstream discussions even among the able non disabled youth. As a result, the needs of youth with disabilities are totally ignored. On the other hand, there have been numerous and frequent reports of incidents of sexual violence, abuse and atrocities perpetrated on young people with disabilities particularly women. Rarely seen and hardly heard young people with disabilities tend to remain voiceless and are made to suffer silently.

This study is an attempt to flag this issue and put it on the agenda for public discussions on youth issues as well as the rights of persons with disabilities. It includes a collation of information and resources based on interviews with young people with disabilities, with parents, special educators/teachers, and
other care providers. It takes into account three major concerns about experiences of youth with disabilities in SHSR i.e. a) Sexual Violence s b) Sexual Health and c) Sexuality

The study used a two-stage sampling process—

- **Stage 1** - To select the partner community based organisations (CBOs) working with and for YwDs
- **Stage 2** - Selection of youth respondents for the study.

Further, based on the parent networks existing in the selected CBOs, parents were carefully chosen and finally teachers/special educators were also included to participate in the study in order to understand their perceptions on sexual health issues of YwDs. The research was carried out at four locations of Assam:

- Guwahati
- Jorhat
- Tezpur
- Duliajan

The findings suggest that there is an abysmal dearth of information or related services on sexual health and sexual rights for people with disabilities. It reiterates that adolescence issues of the YwDs need immediate attention and they should be addressed in a way that also includes parents, special educators/teachers and other caregivers, who in turn, could learn to deal with the youth in a more private and logical way. We also found, there is an encouraging increase in awareness among the YwDs, parents and teachers about sexual violence.

This study also offers some recommendations for the way ahead. Some of these are as follows—

1. Sensitizing people who interact with youth with disabilities.

2. Including comprehensive sexuality education in the institution curriculum for 15+ year old YwDs.

3. Developing a ‘training’ module on Sexual Health and Sexual Rights of youth with Disability with a focus on sensitization for teachers, special educators, NGO staff and caregivers.
4. Developing relevant communication aids for ease of information dissemination among the youth.

We hope that this will be a useful document for people with disabilities, parents, teachers, special educators, activists, care providers, health professionals, academicians, researchers, and policy makers to take the work of affirming the sexual health and rights of people with disabilities forward.
CHAPTER 1
INTRODUCTION

1.1 Youth and sexuality in India

A large number of young people in India are sexually active, but they are ignorant and misinformed about some of the very basic things they need to know about sex\(^1\). Our own engagement with young people in Guwahati and Assam has also shown us that they have a lot of questions and there are hardly any spaces or forums where they can learn and access information, ask questions and clarify their doubts in an open non threatening way. Research studies on the level of sexual knowledge among the youth indicate that a lot of myths prevail, and there is dangerously inaccurate knowledge about contraception and conception which could also be due to their lack of experience. Clearly there is a need for accurate sex information in order for adolescents to make informed decisions and choices about their sexual behaviour. Parents are unable to provide adequate information. Some schools and NGOs have initiated sexual health programs but these are restricted mostly to urban areas.

In the Indian context, sex is always concomitant with social norms, religious restrictions and moral taboos. While young people aged 10–25 years in India represent approximately one-third of the country’s population, very few entities address their sexual information needs. Peers, books, magazines, television and the internet are the most frequently used source of sex information. Boys reported more liberal attitudes and more frequent sexual behaviour than girls. (2)

Renu Adlakha ........

Sexuality, especially of young persons, is considered socially threatening, more in need of control than encouragement and enhancement. Such issues, as sexual expression, sexual intimacy, procreation and contraception, are highly emo-

\(^1\) Rita Banerji blog@www.youthkiazaar.com/2013/11/10-things-indianyouth-need-to-know-sex/
tionally charged and difficult to address. There is also the assumption among adults that sexuality education will arouse insatiable aspirations, lead to over-stimulation and uncontrollable, irresponsible sexual behaviour\(^2\). Professionals are also not immune to cultural assumptions, myths and stereotypes, and may feel resistant to imparting sexually-related information counselling to youth with disabilities.

Children in India are exposed to risk factors that make them sexually violent later in life. The study carried out by International Centre for Research on women; found that 24.5% of Indian men covered by it has engaged in sexual violence at some point and most of them with an intimate partner. It found that sexual aggression including teasing and sexual harassment was high among Indian youth, while alcohol abuse was cited as the second leading influencing factor that led to rape. The study, covering 2,000 men aged 18-59 years. The study found that men who experienced neglect or were abused as children tend to be more sexually aggressive than others. Among Indian men, 34% of those who were sexually abused in childhood report sexual violence perpetration. And 36.8% said they felt neglected as children.

Similarly, sexual abuse is a serious and pervasive social malady in India as it is in many areas of the world today. Child sexual abuse can contribute to abnormal and arrested development, and a wide array of psychological and emotional disorders, that some children and adolescents may experience for a lifetime. In India as in other countries, intra-familial sexual abuse often goes unreported. When this occurs and children are not given the protective and therapeutic assistance they need, they are left to suffer and struggle on their own.

Sexuality of Youth with Disabilities in India

A significant group of adolescents and Youth with Disabilities are not able to access programs targeting sexuality and reproductive health because they do not address the specific concerns of this socially marginalised group. In order to ensure that all citizens of the country are guaranteed the right to health, it is imperative that the concerns of youth with disabilities are mainstreamed into Gouv health and population policies. (Dr. Renu Adlakha http://dnis.org/print_interview.php?interview_id=70)

\(^2\) Dr. Renu Adlakha, Mac Arthur Fellow, http://dnis.org/print_interview.php?interview_id=70
Youth who live with a physical or intellectual disability have to deal with specific issues as they explore and develop their sexuality. Many do so without access to the level of sexual information and education available to their non-disabled peers. Recent research on the sexual health information and educational needs of youth with physical disabilities point to various myths associated with sexuality and sexual health of people with disability (YwD) and the stigma and stereotypes associated with sexuality and disability, sometimes regarded as asexual and at other times as hypersexual they are also faced with the misconceptions of eugenics even though only a small percentage of disabilities are genetic in nature. They are often considered undesirable or less desirable than a non-disabled person. Low self image and practical problems prevent people with disabilities from having fulfilling romantic and sexual relationships. Architectural barriers, transportation difficulties further limit their opportunities for interaction and socialisation. They are also extremely vulnerable to abuse - that includes neglect, physical and emotional and sexual abuse. Although they are often seen as asexual women with disabilities are extremely vulnerable to being sexually abused. Their powerlessness and dependence from the social attitudes and stigma is exploited. It is incorrectly assumed that individuals with disability are sexually inactive or are at less risk of violence or rape than their non-disabled peers.

According to conservative WHO estimates dating from the 1970s, 10% of the world’s population – 650 million people – live with some disability. They have since updated prevalence rate to 15% of whom 2-4% experience significant difficulties in functioning. (http://www.who.int/disabilities/world_report/2011/report/en/)

Persons with disabilities have the same sexual and reproductive health (SRH) needs as other people. Yet they often face barriers to information and services. The ignorance and attitudes of society and individuals, including health-care providers, raise most of these barriers – not the disabilities themselves. In fact, existing services usually can be adapted easily to accommodate persons with disabilities. Increasing awareness is the first and biggest step. Beyond that, much can be accomplished through resourcefulness and involving persons with disabilities in programme design and monitoring. (1).

Sexual and Reproductive Health (SRH) is a fundamental human right.
has been clearly reiterated in Article 25 the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which India has ratified. It clearly states that the State Parties shall provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes. WHO’s global disability action plan 2014-2021 clearly states ‘Better health for all people with disability’. WHO also considers disability as a human rights issue because of the experience of the stigmatization, discrimination and multiple violations, prejudice and disrespect faced throughout their life course (WHO, 2014). However, the SRH rights of Persons with Disabilities (YwDs) have not been adequately addressed unlike their other rights, such as to social integration, education or employment. (1)

1.2 People with Disability: population statistics in India

Census of India, 2011 estimates the YwD population in India to 26.8 million (2.21%). Figure 1.1 shows the proportion of YwD in India to the total population. (Census of India, 2011)

Figure 1.1: Proportion of YwD to Total Population in India, 2011
There are more men (14.9 million or 2.41%) with disabilities as compared to women (11.8 million or 2.01%) in the country. Also, proportion of people with disabilities in rural India (2.24%) is more than in urban areas (2.17%) (Figure 1.2). India has 20.42 lakh children with disabilities aged between 0 and 6 years. Around 71% of them - 14.52 lakh children - are in rural areas. There are 5.9 lakh children with disabilities in cities. Of them, 11.04 lakh are male and 9.38 lakh are female children. Among them, 1.49 lakh children have multiple disabilities (3).

Children with hearing and eyesight impairments form the lion’s share among children with Disabilities. All age groups put together, there are more than 41 lakh children with eyesight problems and hearing disability.

**Figure 1.2: Proportion of YwDs in Rural and Urban settings in India, Census of India 2011**

1.3 Disability in Assam

According to the Census of India, 2011, the total number of people living with disability in Assam is 530,300. Five types of disabilities were surveyed
during this census - Visual, speech, hearing, locomotive and mental disability.

Table 1.3 provides the proportion of the five disabilities in Assam (Census 2011). Most people with disabilities in Assam are visually impaired (53%), followed by people with locomotive disability (17%). People with mental disability constitute 9% of all persons with disabilities in Assam.

**Figure 1.3: Proportion of YwDs by types of disability in Assam, 2011**

Assam has the maximum number of disabled children aged 0-6 years (35,742) among all the North-eastern states (3). Rural areas have more people with disabilities than urban areas across the country, and the disabled population is less than 1.75% of the total population in Assam.

**1.4 Status of violence against people with disabilities in Assam and the Northeast Indian States**

Even though some information is available on violence against persons with disabilities but relevant information about the sexual experiences of YwDs or Youth with Disabilities (YwD) in Assam is absent.
In India many women and girls with disabilities, especially those with intellectual disability, very often reside in mental hospitals and institutions. A recent Human Rights Watch report called for the government to take prompt steps to shift the women from forced institutional care to voluntary community-based services and support. As mentioned earlier stigma and marginalization, poverty, illiteracy, unemployment and the low probability that they will be considered eligible marriage partners, significantly diminish the ability of many individuals with disability to participate in SHSR programmes. Without concerted efforts to address specific challenges faced by such vulnerable groups, the Sustainable Development goals will never be achieved. (4)

An appropriate education system, teaching aids, books in Braille, interpreters for the hearing and speech impaired are still not available for majority of those facing disabilities. In Assam, a greater percentage of people with disabilities live in rural areas. Studies reveal that although a number of statutes relating to people with disability have been enacted in the last two decades, unfortunately these laws are not being implemented properly in the North-east region with even awareness levels remaining abysmally low. These and many other factors bind the majority of individuals with disability in a cage of poverty and prejudice.

Three major concerns get flagged when it comes to experiences of youth with disabilities vis a vis SHSR:

1.5 Sexual violence on youth with disabilities

Youth with disabilities, especially girls and young women are more vulnerable to sexual crimes, and quite often the perpetrators are close relatives caregivers. Such crimes frequently go unnoticed and unreported, as the victims are either scared or unable to speak about it.

1.6 Youth, Disability and Sexual Health

Youth with disabilities are vulnerable to a staggering list of sexual health risks like HIV, other Sexually Transmitted Diseases, adolescent pregnancies, higher substance use and abuse, and sexual assault. The causes could be due to high levels of poverty, low educational levels little or no access to HIV prevention information and healthcare, as well as lack of information about safe sex and
pleasure.

1.7 Sexuality and Youth with Disability

The biggest unspoken issue that youth with disability face is the rigid silence that society maintains regarding their sexuality. Even organizations working for people with disabilities focus on every other aspect but become evasive when it comes to sexual rights. The focus is usually on correction of ‘problems’; for instance, ‘fixing’ sexual deviancy and promiscuity through the use of forced sterilization is a common ‘solution’ that caregivers resort to. (5) (6)
CHAPTER 2
RATIONALE BEHIND THE STUDY

2.1 Study Rationale

The intent to bring forward this discussion and acknowledge the equal rights of the people with disabilities to their sexual expression stands as the rationale behind this project implemented by Foundation for Social Transformation (FST). Recognising the sore need for opportunities and spaces for young people to learn and understand about sexuality and related matters; realising that within this group, the needs of young people with disabilities are largely ignored; and noting that they are a very vulnerable group as evident from frequent media reports of heinous sexual crimes against them, FST initiated this study to call attention to and underscore the need for inclusion of the sexual health and sexual rights of YwDs in Assam into public policy. This study attempts to understand the current situation of sexual and reproductive health, attitudes and knowledge among the YwD, their parents and teachers/caregivers.

Although FST works in all seven states of North East India, keeping in view the budgetary constraints, and our own limitations, we initiated this study in Assam, with the aim of catalysing a state-wide dialogue and advocacy on the issue. The findings from the study will suggest strategies towards redressing the erstwhile silence on this issue and facilitating the discourse. The study will serve as a resource to fill the dismal lack of factual evidence and data and highlight the issues for sexual health and sexual rights of youth with disabilities in Assam, such as the marked absence of support systems for them, when it comes to sexual choice, health and sexual abuse. There is an urgent need to build a dialogue with teachers, parents, caregivers and stakeholders and build their capacity on the issue through trainings. Enhancing capacities of youths with disability to understand these issues is also required.

2.2 Research Objectives

Overall, the objective of this study is to understand the sexual and reproductive health needs of young people with disability (YwD) in Assam, India.
The specific aims are to:

- Examine the sexual and reproductive health knowledge, experiences and needs of young people with intellectual or physical disability.
- Identify barriers to accessing SRH information and services.
- Gauge the level of knowledge and preparedness of parents or caregivers of young people with disability on various SRHR areas and understand the challenges faced by teachers of young people with disability at the institutions and their training needs thereof.
- Suggest specific areas of intervention to equip YwD as well as their parents/caregivers and teachers with complete information and knowledge to take care of their SRH needs.

2.3 Scope of the study

This study will add to the limited work that is available in Assam, and build evidence for developing specific communication materials for the sexual and reproductive health needs of YwD as well as their caregivers and teachers. It will identify gaps in Knowledge Attitude Perceptions (KAP) on sexual and reproductive health, sexuality, self-esteem, and knowledge of the issue. Dissemination of findings among relevant stakeholders will generate awareness at the state level, and enable development of specific training modules for the youth as well as caregivers and teachers, to better handle queries and behaviour of youth with disability both at home and in institutions.

2.4 Limitations of the study

While undertaking this survey, several limitations were faced in obtaining reliable information on questions pertaining to sexuality, sexual behaviour and sexual needs, that tended to limit the scope of the analysis.

The following challenges were encountered during data collection process.

- The process of selecting the institutions for conducting this study was more tedious than expected. There are very few institutions in Assam working with persons with disabilities and only four consented to participate in the study.
- While the original study was proposed to be carried out among 10-25 year old YwD, it was decided to restrict it to 15-25 years since the stakeholders were of the opinion that the questions were unlikely to solicit
relevant responses from the younger age group (10-14 years).

- Finding field investigators for conducting the study was difficult due to the inhibitions and social stigma associated with sexuality and Sexual Health and time and availability was also a factor.

- It was difficult to find male investigators.

- Considerable effort went into making the field investigators comfortable with the questionnaire and ensuring they objectively follow the questionnaire and do not get carried away by emotions during interviews on sensitive topics.

- It was difficult to find respondents including young people with disability and parents of young people with disabilities for the interviews.

- We faced difficulty in arranging interpreters for the hearing and speech impaired youth who were mature and competent to handle the topic of sexuality.

- It was challenging to explain questions and code responses, particularly for participants with Autism, despite selecting investigators for the study from among those who worked with youth with autism. The possibility of certain sensitive questions being misinterpreted or underreported by the investigators cannot be overruled.

- Confidentiality and privacy were compromised while interviewing youth with Autism since their caregivers accompanied them throughout the interviews. Also, consent for the interview was taken from the youth through their caregivers, in such cases.

- The findings of this study cannot be generalized to a larger group since the sample size of this study is very small. However, they do give an indication of the gaps that exist and scope for further research in the area of SRH needs of YwDs.
CHAPTER 3

METHODOLOGY

3.1 Study setting

The research was carried out in Guwahati, Jorhat, Tezpur and Duliajan along with the implementation partner and the community based organisations (CBOs). These four CBOs were selected based on the availability of organisations working for YwD, their network to identify potential respondents, and their willingness to participate in the study. The challenge that the bigger project, of which this research is a part, intends to address in Assam, is the lack of any discourse on the issue of sexual health and rights of youth with disabilities.

3.2 Study participants

This exploratory study was carried out among three key audiences, at the CBOs across the four locations of the study.

- Youth with disability (YwD)
- Parents/caregivers of YwD
- Teachers / special educators working with YwD in the CBOs

3.3 Sampling Methods

This study used a two-stage sampling process—

- Firstly selection of the organisations working with and for YwDs
- Secondly, selection of youth respondents for the study.

Further, based on the parent networks existing in these selected CBOs, parents were selected and finally teachers/special educators / counsellors from the CBOS were also included in the study so as to understand their perceptions on YwDs sexual health issues.

3.4 Method of identifying study participants

We did face problems in identifying and reaching YwD respondents due to difficulties of access and isolation by their families, and they were not all con-
nected to the selected CBOs. Even though Census figures show that there are almost 1.75% people with disabilities in Assam a large majority of them are not reached by the limited number of NGOs and institutions working in the disability sector, that operate mostly in urban and semi urban areas. The coverage of CBOs in rural areas is very thin on the ground. Thus it was decided that the study would include YwD who were connected to the selected CBOs.

a) Selection of CBOs

We identified and listed, organisations catering to YwDs across five different disabilities - Intellectual Disability - earlier referred to as Mental retardation (MR), Cerebral Palsy (CP) Speech and Hearing Impairments, Visual impairment (VI) and ASD (Autism) in Assam. After detailed discussions with each one of them, four were selected for the study. The profile of the four selected Community Based Organisations (CBOs) located at Guwahati, Jorhat, Duliajan and Tezpur is described in the table below (Table 1.1).

<table>
<thead>
<tr>
<th>Profile</th>
<th>Location</th>
<th>Name of the CBO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shishu Sarothi, a premier centre for rehabilitation and training for multiple disabilities, is a registered non-profit voluntary organisation that has been working in the Northeast region of India since 1987. For twenty three years now, Shishu Sarothi has been working towards the many special needs of persons with disabilities- from education to rehabilitation to training, to employment to protection of rights.</td>
<td>Guwahati</td>
<td>Shishu Sarothi- Centre for Rehabilitation and Training for Multiple Disability</td>
</tr>
<tr>
<td>Prerona is a prime institution in Upper Assam, with a vision to make persons with disability efficient in every sphere of life and be entitled to equal rights and a better quality of life. It visualizes a society which is discrimination and barrier free.</td>
<td>Jorhat</td>
<td>Prerona Pratibandhi Shishu Bikas Kendra</td>
</tr>
</tbody>
</table>

www.shishusarothi.org

www.preronao.org.webs.com
| Mrinaljyoti Rehabilitation Centre was established in 1991. It has crossed sixteen glorious years in the service of special children as well as adult persons with disabilities. The organization works with the special children of our Society by offering early intervention, treatment, education and rehabilitation. | Duliajan | Mrinaljyoti Rehabilitation Centre  
www.mrinaljyotiasam.org |
| Sanjivani has been working for children with special needs for more than a decade now. They provide educational and rehabilitation support to children with disabilities. | Tezpur | Sanjivani |

b) **Selection of Youth with Disabilities:** The selection criterion for youth with disabilities was that they should be in the age group 15-25 years and willing to participate in the study. Informed consent was obtained from each youth who qualified as participant, and only after they agreed, were they included in the study.

For the visually challenged youth, the consent form was read out in presence of a person of authority from their respective institutions. In case of a youth with autism, HI, CP or ID, the consent form was read out in presence of their parents and teachers/special educators, and thereafter agreement on the same was sought. For those YwD below the 18 years of age, consent was taken from their parents/guardians.

c) **Selection of parents:** Parents were also selected through the CBO network. Parents too were read the consent form and only after receiving consent, were they included as study participants. Parents who agreed to participate were invited to the CBO on a particular day for administering the questionnaire during individual interviews. This was done so that the study could be conducted in a time-efficient manner.

d) **Selection of Teachers/Special Educators:** Teachers/Special Educators associated with selected CBOs who interacted closely with YwD were approached to be part of the study. The consent form was read out to them and they were included in the Study after permission was received.
Verbal consent was obtained from all the three participant groups, and only when they agreed to participate were they included in the study. No allowances/stipends were provided to any of the participants for taking part in the study. All research ethics were strictly adhered to during the course of the study, including the clause of confidentiality and privacy of all study participants.

3.5 Method of data collection

a) Disability and Age profiling: In order to conduct a situational analysis and understand the sexual health and rights of youth with disabilities, the project team underwent a three day research training. The training encompassed aspects on profiling the disabilities and the age group to be considered, and thereby designing a questionnaire for the target group i.e., youth with disability, parents and teachers/special educators/care givers on addressing issues around sexuality, sexual health and hygiene and sexual violence.

b) Definition of various Disabilities:

Cerebral Palsy: Cerebral palsy is considered a neurological disorder caused by a non-progressive brain injury or malformation that occurs while the child’s brain is under development. Cerebral palsy affects muscles and a person’s ability to control them. Muscles can contract too much, too little, or all at the same time. Limbs can be stiff and forced into painful, awkward positions. Fluctuating muscle contractions can make limbs tremble, shake, or writhe. Balance, posture, and coordination can also be affected by cerebral palsy. Tasks such as walking, sitting, or tying shoes may be difficult for some, while others might have difficulty grasping objects. Other complications, such as intellectual impairment, seizures, and vision or hearing impairment also commonly accompany cerebral palsy.

Mental Retardation: Intellectual disability (ID), also called intellectual development disorder (IDD) or general learning disability, and formerly known as mental retardation (MR), is a generalized neurodevelopment disorder characterized by significantly impaired intellectual and adaptive functioning. Someone with intellectual disability has limitations in two areas. These areas are:

1. Intellectual functioning, also known as IQ, this refers to a person’s ability to learn reason, make decisions, and solve problems;
2. Adaptive behaviours. These are skills necessary for day-to-day life, such
as being able to communicate effectively, interact with others, and take care of oneself.

**Autism:** Autism is a neurodevelopment disorder characterized by impaired social interactions, verbal and non-verbal communications, and restricted and repetitive behaviour. Autism spectrum disorder (ASD) is an umbrella term for a group of complex neurodevelopment disorders of brain development characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviours. Usually manifesting itself by the age of 3, and occurring differently in each child, it is more common in boys than girls and affects one in every 150 children.

**Hearing Impairment (HI):** Is the inability to hear sound adequately due to improper development, damage or disease to any part of the hearing mechanism. It could be due to conductive hearing loss or sensory-neural hearing loss or a combination of causes and could vary from mild to profound impairment and remains largely under identified and under served. HI results in delays in development of speech and language, cognition and learning difficulties.

**Speech and Language Impairment:** Speech and Language impairment could be a result of hearing impairment or associated with other disabilities such as cerebral palsy, Intellectual disability etc. Speech and language Impairment could cause problems of Articulation (lisping, inability to produce some sounds), Fluency (disruption of speech by sounds, syllables or words, phonation problems etc), Voice (abnormality in pitch, resonance, loudness etc) and Language (problems in expressing needs, information and understanding what others say)

**Visually Impaired:** VI refers to people with irretreivable sight and covers a wide spectrum of impairments including total blindness and low vision. VI includes those whose sight might be improved with medical intervention but not those whose sight problems can be corrected with spectacles or contact lenses.

Moderate visual impairment combined with severe visual impairment are grouped under the term “low vision”: low vision taken together with blindness represents all visual impairment.

While profiling the different disabilities, one of the major challenges faced
was to determine which type of disabilities would be included in the study. Although it was felt that young people with all types of disabilities should be included, due to various limitations, like scarcity of qualified field investigators, accommodations in mode of delivering the questionnaire for youth with different disabilities, difficulty in reaching youth with disability who were out of institutions/organisations because of access issues and even isolation and alienation by family as well as reluctance of some institutions to be part of the study, only five disabilities were taken into consideration to represent the larger group. These disabilities were Cerebral Palsy (CP), mild Intellectual Disability (ID), Hearing Impairment (HI), Visual Impairment (VI), and Autism Spectrum Disorder (ASD). This decision was arrived at after detailed discussion and deliberation with Shishu Sarothi and National Foundation of India (NFI).

c) Sample Size

Below is the list showing the final sample target:

Table 1.2 Sample size for the survey

<table>
<thead>
<tr>
<th>P/C**</th>
<th>T*</th>
<th>Total</th>
<th>ASD</th>
<th>HI</th>
<th>VI</th>
<th>Developmental disability (low degree of ID &amp; CP)</th>
<th>Place</th>
<th>CBO</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>10</td>
<td>40</td>
<td>10</td>
<td>8</td>
<td>5</td>
<td>17</td>
<td>Guwahati-Shishu Sarothi</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>10</td>
<td>20</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>Tezpur</td>
<td>Sanjivani Jodhat</td>
</tr>
<tr>
<td>10</td>
<td>10</td>
<td>20</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>Prerona Pratibandhi Shishu Bikash Kendra</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>10</td>
<td>20</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>Duliajan</td>
<td>Mrinalyoti Rehabilitation Centre</td>
</tr>
<tr>
<td>40</td>
<td>40</td>
<td>100</td>
<td>25</td>
<td>23</td>
<td>20</td>
<td>32</td>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>

*T = Teachers/Special Educators
**P/C = Parents/Caregivers
d) Age Profile

Although, the project was proposed to be carried out among youth with disability between the ages of 10 to 25 years. However during discussions with stakeholders involved, it was agreed that a 10 year old child may not be able to respond to questions related to issue of sexuality and hence the response may become irrelevant. Therefore a conscious decision was taken to increase the age bracket from 15-25 years of age for the target group.

3.6 Study tools

a) Questionnaire

A semi-structured questionnaire was developed for each of the three target audiences to record the qualitative inputs, besides the quantitative data. The process of developing the questionnaire for the study involved rigorous steps.

At the first level, in-depth discussions were held with the project implementing partner Shishu Sarothi, its staff members and few parents of young people with disabilities. The team involved with the project did an extensive literature review that included various information, case studies and resource material available. Post these discussions and research, all gathered information were shared with TARSHI and Point of View, for feedback.

The questionnaire was finalised after several draft phases and with inputs received from Point of View, Shishu Sarothi and National Foundation of India (NFI). On finalisation, the questionnaire was translated into the local language, Assamese and a Braille version was developed for the youth with VI. Besides these, show cards (depicting body parts, various stages of growing up, various uses of mobile phones) were developed.

b) Developing the consent forms

Keeping in mind the sensitivity and confidentiality of the questionnaire and the corresponding response from each target group, consent forms with details explaining the purpose of the study were developed. A separate consent form for youth under the age of 18 years was also developed. Consent for this particular group was sought from the parents.
Following the preparation of the final questionnaire, the project team was trained on research protocols, questionnaire administration, response coding and data collection.

c) Pilot Study

A pilot study with one youth with CP and one youth with ID at Shishu Sarothi was conducted. The pilot study revealed the following:

1. The youth responded to the questions, but the whole process involved time and patience.

2. Often, even if the respondent said a ‘yes’ or ‘agreed’ to a question, it was difficult to understand the relevance of their agreement.

3. Responses were more forthcoming to questions which had pictorials options.

4. The notion that the respondent who has a disability may not respond at all, was challenged during the pilot.

c) Selection of Field Investigators

Four field investigators from each of the four project CBOs located at Guwahati, Jorhat, Tezpur and Duliajan were selected. Most of the investigators selected were special educators. The selection process was quite challenging, as they were few of them in the first place and it was difficult to find investigators who were comfortable with and aware of the issue of sexuality without stigma or prejudice and agreeable to do the study. Post recruitment, the field investigators attended a three-day demystification workshop organised at Guwahati. During the first two days, an intensive discussion on sexuality, gender, sexual health and sexual violence was facilitated by Ms. Sathyasree Goswami- Project Director, Youth Innovation Fund at NFI. The idea was to challenge the investigators’ thinking and beliefs, preconceived notions and prejudices around the issue and arrive at unbiased conclusions. On the third day we introduced and oriented them to the questionnaire and the consent form. They were trained to administer the questionnaire with each target group, code responses and collect data as per standard research protocol. Mock interviews were also conducted during the training. Accommodations were made for visually impaired youth, by
printing the questionnaires in Braille, sign language interpreters were allotted for HI respondents and caregivers were allowed to sit with respondents with ASD

f) **Data collection:** The data collection was carried out over the span of one month (15th June 2015 to 10th July 2015).

g) **Response Rate:** The response rate for a study of this nature was very good at 85% for youth and teachers respectively, and 100% for the parents. The youth who did not respond were mostly those with cerebral palsy. They could not comprehend the questions thus making it difficult to collect data.
CHAPTER 4

FINDINGS

[Young people’s Knowledge, Attitudes and Perceptions on sexual Health and Rights]

4.1 Profile of youth with disability:
Table 2.1 profiles the distribution of Youth with Disability (YwD) across disabilities. A total of 82 YwD were interviewed with 19 had ID, 13 had CP, 18 were VI, 22 had HI and 10 had ASD. While 56% of the youth interviewed were boys, there was a significant number of girls too who consented to be part of the study (44%). A total of 32 youth had more severe disabilities. The average family size of the youth with disability was reported as 8. The mean years of attending school/special education facilities, as reported by the YwD is 8 years. This includes either formal or informal schooling.

<table>
<thead>
<tr>
<th>Description</th>
<th>Types of disabilities - N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ID(19)</td>
</tr>
<tr>
<td>Sex of respondent</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11(23.9)</td>
</tr>
<tr>
<td>Female</td>
<td>8(22.2)</td>
</tr>
<tr>
<td>Degree of disability</td>
<td></td>
</tr>
<tr>
<td>Low degree (mild)</td>
<td>18(36.7)</td>
</tr>
<tr>
<td>High degree (moderate to profound)</td>
<td>1(3.1)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>&lt; 18</td>
<td>8(21.6)</td>
</tr>
<tr>
<td>18-21</td>
<td>3(13.0)</td>
</tr>
<tr>
<td>21-23</td>
<td>6(46.2)</td>
</tr>
<tr>
<td>24+</td>
<td>2(22.2)</td>
</tr>
<tr>
<td>Religion</td>
<td>Hindu</td>
</tr>
<tr>
<td>-------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Muslim</td>
<td>0</td>
</tr>
<tr>
<td>Ever attended Special or Regular school</td>
<td></td>
</tr>
<tr>
<td>Formal school</td>
<td>12(19.7)</td>
</tr>
<tr>
<td>Informal school</td>
<td>7(38.9)</td>
</tr>
<tr>
<td>No school attended</td>
<td>0</td>
</tr>
<tr>
<td>Currently attending one of the schools</td>
<td></td>
</tr>
<tr>
<td>Special school (Co-ed)</td>
<td>12(24.5)</td>
</tr>
<tr>
<td>Regular school (only girls)</td>
<td>0</td>
</tr>
<tr>
<td>Regular school (co-ed)</td>
<td>2(22.2)</td>
</tr>
<tr>
<td>Informal school (co-ed)</td>
<td>3(27.3)</td>
</tr>
<tr>
<td>Informal school (at home)</td>
<td>1(100.0)</td>
</tr>
<tr>
<td>Informal school (group study)</td>
<td>0</td>
</tr>
<tr>
<td>If currently working</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0</td>
</tr>
<tr>
<td>Type of work</td>
<td></td>
</tr>
<tr>
<td>Art teacher</td>
<td>0</td>
</tr>
<tr>
<td>Music teacher</td>
<td>0</td>
</tr>
<tr>
<td>Private job</td>
<td>0</td>
</tr>
<tr>
<td>Range of income earned</td>
<td></td>
</tr>
<tr>
<td>Less than Rs. 5000</td>
<td>0</td>
</tr>
<tr>
<td>With whom do you usually spend your free time?</td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>3(42.9)</td>
</tr>
<tr>
<td>Mother</td>
<td>8(30.8)</td>
</tr>
<tr>
<td>Sibling</td>
<td>0</td>
</tr>
<tr>
<td>Friends/relative</td>
<td>8(22.9)</td>
</tr>
<tr>
<td>Caregiver</td>
<td>0</td>
</tr>
<tr>
<td>---------------------------</td>
<td>---</td>
</tr>
<tr>
<td>Teacher</td>
<td>0</td>
</tr>
<tr>
<td>Own children</td>
<td>0</td>
</tr>
<tr>
<td>Others (wife/husband)</td>
<td>0</td>
</tr>
<tr>
<td><strong>With whom are you most comfortable to discuss or talk about your health issues or growing up issues or personal issues</strong></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>2(28.6)</td>
</tr>
<tr>
<td>Mother</td>
<td>9(29.0)</td>
</tr>
<tr>
<td>Older siblings</td>
<td>0</td>
</tr>
<tr>
<td>Friends</td>
<td>6(19.4)</td>
</tr>
<tr>
<td>School teacher</td>
<td>1(25.0)</td>
</tr>
<tr>
<td>Caregiver</td>
<td>0</td>
</tr>
<tr>
<td>Others (wife/husband)</td>
<td>1(50.0)</td>
</tr>
<tr>
<td>All the above</td>
<td>0</td>
</tr>
<tr>
<td>With no one</td>
<td>0</td>
</tr>
<tr>
<td>With self</td>
<td>0</td>
</tr>
</tbody>
</table>

Seven YwD (1 CP, 5 VI, 1 HI) were currently employed. All of them were drawing less than Rs.5000 as monthly salary. On the issue of socializing, most reported spending their free time with friends and relatives (35), followed by mothers being preferred companions (26). It is evident that mothers and friends ranked the highest among those that YwDs were most comfortable to discuss or talk about their health issues, growing up issues, personal issues.
4.2 Access to communication media

Almost all YwDs indicated having access to television at home. The most popular programmes watched were movies, soap operas, news and sports channels. Some (7) also reported watching wildlife programs, cartoons and songs (music) on television. Only 11 youth had access to the internet, most of whom were Hearing Impaired (6). All of them named Google and Facebook as popular internet sites that they visit the most. On mobile phone use, 42 (51%) youth reported having access to a mobile phone. One out of three hearing impaired youth owned a phone, followed by visually impaired youth (10). Table 2.2 describes mobile phone ownership and use among participants.
**Table 2.2: Ownership and use of mobile phones (N=82)**

<table>
<thead>
<tr>
<th>Description</th>
<th>Types of disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ID(19)</td>
</tr>
<tr>
<td>Own a mobile phone</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7(16.7)</td>
</tr>
<tr>
<td>B5. What do you use the Mobile phone most for?</td>
<td></td>
</tr>
<tr>
<td>Calling up friends</td>
<td>0</td>
</tr>
<tr>
<td>Calling up family</td>
<td>1</td>
</tr>
<tr>
<td>Messaging</td>
<td>0</td>
</tr>
<tr>
<td>Playing games</td>
<td>1</td>
</tr>
<tr>
<td>Click pictures and listen to music</td>
<td>5</td>
</tr>
</tbody>
</table>

Mobile phones were used mostly for messaging (12), to connect and talk with family and friends or to click pictures and listen to music (9 each). A few also used it to play games (3).

**4.3 Learning about our bodies and attraction**

In order to better evaluate whether YwD are aware and understand growing up issues, the study participants were shown show-cards of male and female bodies depicting different stages of growth. They were asked a series of questions pertaining to the physiological changes while growing up, and changes in male and female bodies. This segment details findings from the section ‘Know your body’.

A majority (89%) of them indicated understanding of the fact that all human beings undergo bodily changes as they grow and they had noticed changes in their own bodies as well (96.3%). Two out of three study participants, across all disabilities, felt that it is alright to explore one’s body.

**Anecdotal example:** A student (boy) from Shishu Sarothi was almost caught kissing (about to kiss) another student (girl) by the teacher. The girl and the boy have attained puberty. The teacher observed that the girl likes to sit next to
the boys and felt attracted towards them. The boy likes to stare at girls. Since the special educator caught them before they could actually kiss, they were made to sit separately. Both blamed the other one for the incident. The parents of both the children were informed. The girl’s mother was utterly embarrassed. She was advised to keep calm and not over react to the situation as the girl has her needs. Both sets of parents were informed that the children will be kept in check while at Shishu Sarothi, but the parents would have to take care of them when outside Shishu Sarothi.

On the topic of sexual attraction, most young people with disabilities said that they felt happy to see another person from either the same or opposite sex. This of course could also imply that they are craving for company at a given time, and is not conclusive. However, more than three-fourth of study participants also confessed to a feeling of attraction towards the person, who they felt happy to see. Most of the time this person is non-disabled (61%), as reported.

Further questions on relationships revealed interesting answers. A majority (87%) young YwDs felt that people belonging to the opposite sex could be friends with each other and also felt that it was alright for YwD to have a girl/boyfriend.

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

With regard to discussions about growing up, three out of four YwD felt that it was normal and acceptable to discuss growing up issues. However, less than half (48%) respondents felt comfortable in discussing such topics. (Table 2.3).
Table 2.3: Awareness of one’s body, attraction experienced and discussion about growing up by YwDs (Number of respondents=82)

<table>
<thead>
<tr>
<th>Description</th>
<th>N</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>As you are growing up, do you feel/notice any change happening to your body? (Yes)</td>
<td>79</td>
<td>96.3</td>
</tr>
<tr>
<td>Is it ok to explore your body? (Yes)</td>
<td>55</td>
<td>67.1</td>
</tr>
<tr>
<td>Do you think that every human being undergoes bodily changes as they grow? (Yes)</td>
<td>73</td>
<td>89.0</td>
</tr>
<tr>
<td>Do you feel happy when you see a certain person from the opposite sex/same sex? (Yes)</td>
<td>76</td>
<td>92.7</td>
</tr>
<tr>
<td>Do you feel yourself getting attracted to that person as mentioned above? (Yes)</td>
<td>62</td>
<td>75.6</td>
</tr>
<tr>
<td>Are these people (friends/actor/celebrity) whom you feel attracted towards, disabled or non-disabled?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disabled</td>
<td>235</td>
<td>28.06</td>
</tr>
<tr>
<td>Non-disabled</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Do you think girls and boys can be friends with each other? (Yes)</td>
<td>71</td>
<td>86.6</td>
</tr>
<tr>
<td>Is it alright for a person with disability to have girlfriend or boyfriend? (Yes)</td>
<td>67</td>
<td>81.7</td>
</tr>
<tr>
<td>Is it normal for a person with disability to discuss about growing up issues? (Yes)</td>
<td>62</td>
<td>75.6</td>
</tr>
<tr>
<td>How comfortable are you discussing these growing up issues?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfortable</td>
<td>39</td>
<td>47.6</td>
</tr>
<tr>
<td>Uncomfortable</td>
<td>37</td>
<td>45.1</td>
</tr>
<tr>
<td>Not sure</td>
<td>4</td>
<td>4.9</td>
</tr>
</tbody>
</table>

4.4 Importance of discussing issues around growing up with YwD

All study respondents were asked to comment on their views about discussing growing up issues with people with disabilities. Overall, 63 YwDs (77%) felt
that it is important to discuss issues around growing up, menstruation, sex, love, relationship, attractions, safe touch, unsafe touch, marriage and violence with them. Only four respondents felt that it was not important. (Table 2.4)

Table 2.4: Number of respondents who were asked whether it is important to discuss growing-up issues (Number of respondents=82)

<table>
<thead>
<tr>
<th>How important are discussions on growing up</th>
<th>ID(19)</th>
<th>CP(13)</th>
<th>VI(18)</th>
<th>HI(22)</th>
<th>ASD(10)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Important</td>
<td>14</td>
<td>11</td>
<td>14</td>
<td>18</td>
<td>6</td>
<td>63</td>
</tr>
<tr>
<td>Not important</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Not sure/Can't say</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>TOTAL</td>
<td>19</td>
<td>13</td>
<td>18</td>
<td>22</td>
<td>10</td>
<td>82</td>
</tr>
</tbody>
</table>

Those who were of the opinion that it is important to get this information were asked who they would prefer as a source of information for these issues. Majority of the YwDs (31) felt that their mothers would be the preferred person for talking about issues of and growing up and relationships. Friends were the next best source, as reported by 23 persons, mainly CP, VI and DM youth. Teachers were mentioned by only 13 youth, as a possible source for information and discussion.

Talking about sex

Questions pertaining to knowledge, perceptions and behaviour about sex were asked only to respondents over 18 years of age. Of the total sample, 45 respondents were over 18 years of age. (Table 2.5).

Anecdotal example: A 25 yrs. old boy with cerebral palsy and mental retardation would touch a girl's hand for stimulation and at the same time comment that he has seen her in the movie. He would try to grab any girl's hand for sexual stimulation.

Most of the participants (40) over 18 years had heard of the word 'sex'. Among those who had heard of the word 'sex', 77% of the respondents across all dis-
abilities also felt that a person with disability 'can' indulge in sex. However, only 8 male respondents were aware of 'nightfall'.

On the question of whether it was alright for a non-disabled person to indulge in sex with a person with a disability, 24 youth, a little less than half, were in agreement. Most of the youth who agreed to this statement Had a physical disability, they were either VI or HI. On the other hand, an equal number of youth (24) were also of the opinion that if a person with disability shows inclination towards sex, (s)he will be termed a 'bad person'. However, most (28 persons) also felt that no one could force any other person for sex.

It was observed that most participants were very trusting in nature. A majority feel that if a non-disabled person approaches them, it will be either to help them, or to be friends or both. Only three youth were of the view that a harmful intent is a possibility.
<table>
<thead>
<tr>
<th>Questions</th>
<th>ID(11)</th>
<th>CP(6)</th>
<th>VI(10)</th>
<th>HI(15)</th>
<th>ASD(3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you heard of the word 'Sex'?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8(20.0)</td>
<td>4(10.0)</td>
<td>10(25.0)</td>
<td>15(37.5)</td>
<td>3(7.5)</td>
</tr>
<tr>
<td>Do you think a person with disability can indulge in Sex?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4(11.4)</td>
<td>5(14.3)</td>
<td>9(25.7)</td>
<td>14(40.0)</td>
<td>3(8.6)</td>
</tr>
<tr>
<td>A non-disabled person will be alright having sex with a person with disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>3(12.5)</td>
<td>4(16.7)</td>
<td>8(33.3)</td>
<td>7(29.2)</td>
<td>2(8.3)</td>
</tr>
<tr>
<td>Disagree</td>
<td>2(20.0)</td>
<td>2(20.0)</td>
<td>1(10.0)</td>
<td>5(50.0)</td>
<td>0</td>
</tr>
<tr>
<td>Not sure</td>
<td>6(54.5)</td>
<td>0</td>
<td>1(9.1)</td>
<td>3(27.3)</td>
<td>1(9.1)</td>
</tr>
<tr>
<td>If a girl/boy with disability wants to have sex, he/she will be termed as a bad person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>6(25.0)</td>
<td>2(8.3)</td>
<td>4(16.7)</td>
<td>11(45.8)</td>
<td>1(4.2)</td>
</tr>
<tr>
<td>Disagree</td>
<td>1(6.7)</td>
<td>3(20.0)</td>
<td>6(40.0)</td>
<td>4(26.7)</td>
<td>1(6.7)</td>
</tr>
<tr>
<td>Not sure</td>
<td>3(60.0)</td>
<td>1(20.0)</td>
<td>0</td>
<td>0</td>
<td>1(20.0)</td>
</tr>
<tr>
<td>Do you think a person (boy/girl) can force another person (boy/girl) to have sex with (him/her)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5(35.7)</td>
<td>1(7.1)</td>
<td>3(21.4)</td>
<td>3(21.4)</td>
<td>2(14.3)</td>
</tr>
<tr>
<td>No</td>
<td>4(14.3)</td>
<td>5(17.3)</td>
<td>6(21.4)</td>
<td>12(42.9)</td>
<td>1(3.6)</td>
</tr>
</tbody>
</table>

41
<table>
<thead>
<tr>
<th>CS/DK</th>
<th>2(66.7)</th>
<th>0</th>
<th>1(33.3)</th>
<th>0</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think if a non-disabled person talks to you, it will be for one or more of the following reasons?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some help</td>
<td>8(20.5)</td>
<td>6(15.4)</td>
<td>11(28.2)</td>
<td>11(28.2)</td>
<td>3(7.7)</td>
</tr>
<tr>
<td>Friendship</td>
<td>11(26.8)</td>
<td>7(17.1)</td>
<td>9(22.0)</td>
<td>10(24.4)</td>
<td>4(9.8)</td>
</tr>
<tr>
<td>Harmful intention</td>
<td>1(33.3)</td>
<td>0</td>
<td>1(33.3)</td>
<td>1(33.3)</td>
<td>0</td>
</tr>
<tr>
<td>To observe/watch/see</td>
<td>0</td>
<td>0</td>
<td>1(50.0)</td>
<td>1(50.0)</td>
<td>0</td>
</tr>
<tr>
<td>To generally talk</td>
<td>0</td>
<td>1(50.0)</td>
<td>0</td>
<td>0</td>
<td>1(50.0)</td>
</tr>
</tbody>
</table>

**Note:** In all multiple response questions, the total percentage exceed 100.0

### 4.5 Experience of sexual abuse by YwD

In an attempt to explore whether young YwDs had ever experienced any form of sexual abuse, a list of easily articulated questions were asked. Table 2.5 gives a snapshot of the questions and the responses given by the respondent.

**Anecdotal example:** Sexual abuse has become a very common problem in today's society. The victims are usually minor or children, unaware of wrong doing and do not report the same to their parents or guardians. Many a time the perpetrators, who is usually a close relative, friend or a frequent visitor takes undue advantage of the victim by either promising them gifts or favours or otherwise threatening them. The case mentioned below is also one of them. Reena (name changed), is 17 years of age, suffering from hearing impairment and lives with her parents and sister in Dholla. The case has been referred by Dholla police station. Dholla is a small village in Duliajan. Reena's friend Puja (name changed) and her brother Nitin (name changed) often visited Reena. Reena and Nitin developed a close relationship, wherein they also got physical involved. The boy promised Reena that he would marry her and they would have a bright future together. Soon after, Reena became pregnant and Nitin absconded when he heard the news. Reena was left helpless and could not even share her situation with her parents. Soon it became difficult for Reena to hide her pregnancy from her parents. Parents registered a case under Dholla police
station. It was during this time that Mrinaljyoti Rehabilitation Centre provided a speech therapist to help Reena share her predicament in front of the police.

Of the total 82 YwD respondents, 70% had heard about the word 'sexual violence'. Three out of four youth respondents had reported understanding safe touch and unsafe touch and the difference between the two (81%), which is quite heartening.

Table 2.6: Knowledge about sexual abuse among YwD (N=82)

<table>
<thead>
<tr>
<th>Description ('Yes' responses)</th>
<th>Responses N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whether heard of the word 'sexual violence'</td>
<td>57 (69.5)</td>
</tr>
<tr>
<td>Whether know what safe touch is</td>
<td>61 (74.4)</td>
</tr>
<tr>
<td>Whether know what unsafe touch is</td>
<td>62 (75.6)</td>
</tr>
<tr>
<td>Whether can differentiate between safe and unsafe touch</td>
<td>66 (80.5)</td>
</tr>
</tbody>
</table>

Table 2.6 gives a snapshot of personal experiences of YwD with regard to sexual violence. About 17% or 14 respondents reported about being touched inappropriately by someone, which made them uncomfortable. Most of them reported such incidents occurring in the institute/organisation (7), followed by home (4). One of each group reported such experiences in the village, neighbourhood or at a friend's place. Out of the 14 respondents who reported having been touched inappropriately, 12 reported knowing the perpetrator. Half of those who experienced this, felt threatened by this experience. Further, only 8 respondents shared or discussed about this experience with someone - 4 with his/her mother, 1 with his father, and 3 had shared the incident with their teacher/special educator. However, except two, none of the other confidantes had taken this report seriously and they had ignored, made fun of the incident or calmly listened. The two caregivers who did take some action reported it to the highest institute authority. (Not shown).
Table 2.7: Personal experience of sexual abuse among YwD (N=82)

<table>
<thead>
<tr>
<th>Description</th>
<th>Responses N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whether have been touched in a manner that made one feel uncomfortable</td>
<td>14 (17.1)</td>
</tr>
<tr>
<td>Place where incident occurred</td>
<td></td>
</tr>
<tr>
<td>At Institute</td>
<td>7</td>
</tr>
<tr>
<td>At home</td>
<td>4</td>
</tr>
<tr>
<td>Village</td>
<td>1</td>
</tr>
<tr>
<td>Neighbourhood</td>
<td>1</td>
</tr>
<tr>
<td>At friend’s home</td>
<td>1</td>
</tr>
<tr>
<td>Whether perpetrator known to self (Yes)</td>
<td>12</td>
</tr>
<tr>
<td>Whether felt threatened</td>
<td>7</td>
</tr>
<tr>
<td>Whether discussed this incident with someone</td>
<td>8</td>
</tr>
<tr>
<td>Whom discussed with</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>4</td>
</tr>
<tr>
<td>Teacher</td>
<td>1</td>
</tr>
<tr>
<td>Friend</td>
<td>3</td>
</tr>
<tr>
<td>Reaction of the person with whom discussed</td>
<td></td>
</tr>
<tr>
<td>Ignored</td>
<td>2</td>
</tr>
<tr>
<td>Made fun of it</td>
<td>4</td>
</tr>
<tr>
<td>Calmly listened</td>
<td>2</td>
</tr>
</tbody>
</table>

Social interaction among YwD: All 83 respondents were asked questions pertaining to their social skills and ability to make friends. Most of them (95%) said that they liked making friends; majority (71%) had friends who were both disabled and otherwise. About 22% YwD had friends, who were with them in the institute/CBO and had some form of disability.

Talking about love, marriage, crushes and relationships: While most (77%) YwDs reported that they liked talking about love, attraction, crush or marriage with someone, mostly with their friends (58%), about half of them also revealed
that they have tried to discuss their feelings with the person towards whom they felt attracted to. Interestingly, 19% youth equated sex to marriage. Further, only 27% of respondent youth were ever exposed to educational sessions pertaining to sexuality and sexual health. However, most of them (77%) felt that it is very important to have such sessions in their institutes/organisations.

4.6 Sexual health

Menstruation and menstrual hygiene: All female participants of the study (N=36) were asked questions pertaining to their menarche and menstrual hygiene. The average age of menarche for our respondent girls is 12.4 years. About 67% girls had prior information of what to expect during menstruation, this mostly being explained to them by their mothers. While about 72% girls managed menstrual cycle on their own, the rest (10) needed help during those days. Among those who did need help, 5 girls reported feeling very embarrassed to seek help while two of them felt dependent.

With regard to menstrual hygiene, 19% girls used old cloth as protection during their periods, 17% used locally prepared napkins. However majority of them used branded sanitary napkins for menstrual protection.

Pregnancy and contraception: In an attempt to study the respondents’ awareness on issues concerning pregnancy and contraception, a series of questions were asked on a three point scale. The table below gives information of questions that were asked and the responses therein, from respondents over 18 years of age.

It was heartening to note that majority (71%) of the youth had knowledge of how babies were born. Almost half of them had discussed this with their family or caregivers. Also, their views on having sex was quite liberal, with about 47% youth over 18 years indicating that it was alright to have sex, provided a protection was used. About 20% boys had seen a condom.

Further, questions on contraceptives had a three point scale (Agree/Disagree/Don’t Know-Can’t Say). The table presents only the ‘Agree’ responses. At least two out of five youth believe that condoms are effective against pregnancies, that they are meant for boys with disabilities too, and that they are also an effective way to protect against STDs. About 4% youth believe that a condom
can be used more than once, and about 16% youth felt it is embarrassing to buy or procure a condom. (Table 2.7)

Photo description: Teachers at Shishu Sarothi teaching the students how to clean one’s body

Table 2.8: Information pertaining to pregnancy and contraception from youth over 18 years of age (N=45). The table presents only the ‘Agree’ responses.

<table>
<thead>
<tr>
<th>Pregnancy related questions</th>
<th>Yes (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know where babies come from?</td>
<td>71.1</td>
</tr>
<tr>
<td>Have you ever discussed about how babies are born?</td>
<td>48.9</td>
</tr>
<tr>
<td>Is it alright for boys and girls to have sex with each other provided that they use methods to prevent Pregnancy?</td>
<td>46.7</td>
</tr>
<tr>
<td>Condoms are an effective method of preventing pregnancy</td>
<td>43.2</td>
</tr>
<tr>
<td>Condoms are also meant for boys/men with disabilities</td>
<td>44.4</td>
</tr>
<tr>
<td>A condom can be used more than once</td>
<td>4.4</td>
</tr>
<tr>
<td>It would be too embarrassing for a person with disability to buy or obtain condom</td>
<td>15.6</td>
</tr>
<tr>
<td>Condoms are an effective way of protecting against sexually transmitted diseases</td>
<td>40.0</td>
</tr>
</tbody>
</table>
CHAPTER 5

PARENTAL PERCEPTIONS

5.1 Parents’ perceptions on Sexual Health and Sexual Rights of Youth with Disabilities

Parents are the first teachers of their children, and in a way they teach their child many things about sexuality from the day they are born. Children learn from the way they are touched by others; the way their bodies respond to them; behaviour that is acceptable and unacceptable to their families; language (words/phrases) used/not used by family members to refer to parts of the body. They learn by watching the interactions and relationships around them. Keeping this context in mind, we felt it was important to reach out to a sample of parents of YwD to understand their perceptions with regard to sexuality, sexual health and rights of the youth with disability.

As mentioned in the Methodology chapter, a total of 41 parents were randomly selected based on their availability and inclination to participate in the study. Verbal informed consent was taken from all parents, and consenting parents/care-givers were brought to a common place at the CBO/institute at their convenience and research administered the tools individually.

The following sections detail the parent’s socio-economic profile, communications within family, and discussions around knowing and exploring your body, relationships, health and hygiene, health education and violence.

5.2 Socio-economic and demographic profile of parents

Table 3.1 gives an overview of the profile of the participating parents. Most were mothers (81%); of the 8 male respondents, 7 were fathers of YwD and 1 was the brother who was the caregiver of a YwD; mean age of parents was 42 years. About 34% parents attended high school, 32% are graduates. Only 1 person has a postgraduate degree. Majority (95%) belonged to the Hindu religion; only two families were from the Muslim faith (not shown). Most mothers were homemakers/housewives. The average monthly family income is Rs. 15,557.
With regard to number of children born and living, 29% had 1 child who had a disability; about 44% parents had 2 children of which one had a disability. Only 1 family had 5 children. (Not shown). Parents reported the average age of their child with disability as 16 years (Age range 4 years - 29 years). Over half (51%) of the children with disability were male.

On types of disability, it was found that 46% parents had a child with ID, 25% parents had a child with CP. Majority (88%) attended special schools. the rest of them received home-schooling. (Table 3.1).

Table 3.1 Socio-economic and demographic profile of parents (N=41)

<table>
<thead>
<tr>
<th>Description</th>
<th>N  (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8 (19.5)</td>
</tr>
<tr>
<td>Female</td>
<td>33 (80.5)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 35</td>
<td>9 (22.0)</td>
</tr>
<tr>
<td>36-45</td>
<td>18 (43.9)</td>
</tr>
<tr>
<td>45+</td>
<td>14 (34.1)</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
</tr>
<tr>
<td>Primary (1-4 years)</td>
<td>2 (4.9)</td>
</tr>
<tr>
<td>Middle (5-7 years)</td>
<td>3 (7.3)</td>
</tr>
<tr>
<td>High School (8-10 years)</td>
<td>14 (34.1)</td>
</tr>
<tr>
<td>Senior Secondary (11-12 years)</td>
<td>8 (19.5)</td>
</tr>
<tr>
<td>Graduate</td>
<td>13 (31.7)</td>
</tr>
<tr>
<td>Post-graduate</td>
<td>1 (2.4)</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
</tr>
<tr>
<td>Housewife</td>
<td>25 (60.9)</td>
</tr>
<tr>
<td>Service</td>
<td>8 (19.5)</td>
</tr>
<tr>
<td>Business (interior designer, shop and small business)</td>
<td>7 (17.0)</td>
</tr>
<tr>
<td>Vocational Training</td>
<td>1 (2.4)</td>
</tr>
<tr>
<td><strong>Monthly Family Income (INR)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 10000</td>
<td>11 (26.8)</td>
</tr>
<tr>
<td>10000-15000</td>
<td>7 (17.1)</td>
</tr>
<tr>
<td>15000-20000</td>
<td>8 (19.5)</td>
</tr>
</tbody>
</table>
Parents were asked how much time they spent especially with their child with disability during the day. They reported spending about 5 hours per day (Not shown). We asked if there was any discussions specific to 'knowing one's body, growing up stages, sex and sexuality and sexual rights' during their interactions and time spent with their child. Table 3.2 highlights responses against each of the questions asked.

**Anecdotal example:** Rupa (name changed), is 23 years old and stays with her grandparents in Jorhat. Earlier she used to stay with her parents, but since they got divorced, the mother started staying separately. The father got married to his own sister-in-law. The mother also later remarried and did not want to take Rupa along with her. She ended up staying with her grandparents, though her mother and stepfather would visit her frequently. Rupa has Cerebral Palsy.

One day, a social worker from Prerona visited Rupa for regular updates and found her to be somewhat scared and aloof. After much effort and probing, Rupa shared that during one of the visits, her stepfather, had forceful sex with her. On hearing this, the social worker reported the matter to Prerona authorities. Rupa’s grandmother was called to discuss the matter as it was of serious concern.
On hearing about the incident, the grandmother decided to ask for financial compensation from the accused. When she confronted the step-father and asked him to pay the compensation, he refused to do so. Fearing that the incident would get disclosed to the entire village or reported to the police, he blackmailed Rupa’s grandmother by threatening to divorce her daughter. In order to save the daughter’s marriage, the case was not further reported by the grandmother.

Table 3.2: Knowing and Exploring your body, Relationships, Health & Hygiene, Health Education and Violence (N=41)

<table>
<thead>
<tr>
<th>Description</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness among parents (Yes)</td>
<td>41(100.0)</td>
</tr>
<tr>
<td>Discussions about growing up with able bodied child (Yes)</td>
<td>22 (53.7)</td>
</tr>
<tr>
<td>Discussions about ‘growing up’ with child with disability (Yes)</td>
<td>30 (73.2)</td>
</tr>
<tr>
<td>Discussions about relationships, love, attraction, crushes &amp; marriage with child with disability (Yes)</td>
<td>19 (46.3)</td>
</tr>
<tr>
<td>Discussion about Health &amp; Hygiene with child with disability (Yes)</td>
<td>30 (73.2)</td>
</tr>
<tr>
<td>Discussion about Violence &amp; Safety</td>
<td>26 (63.4)</td>
</tr>
<tr>
<td>Discussion about Body &amp; Medical Treatment with able bodied child</td>
<td>12 (29.3)</td>
</tr>
<tr>
<td>Discussion about Body &amp; Medical Treatment with child with disability</td>
<td>13 (31.7)</td>
</tr>
<tr>
<td>Awareness about bodily changes, physical and emotional requirement of child with disability (Yes)</td>
<td>38(92.7)</td>
</tr>
<tr>
<td>Child with disability observing self in the mirror (Yes)</td>
<td>31 (75.6)</td>
</tr>
<tr>
<td>Child with disability seen exploring self (Yes)</td>
<td>20 (48.8)</td>
</tr>
<tr>
<td>Child with disability requiring assistance in personal task (Yes)</td>
<td>32 (78.0)</td>
</tr>
</tbody>
</table>
Child with disability complaining of inappropriate touch (Yes) | 5 (12.2)

All parents as well as the single male caregiver (brother) were aware of topics and issues around knowing one’s body, relationships, health and hygiene, and health education. It was heartening to note that while over half of the parents interviewed, discussed growing-up issues with their able bodied children (54%), about three out of four parents discussed these issues as well as health and hygiene topics with their child with disability too. However, only 19 parents (46%) talked about relationships, love, attraction, crushes, and marriages with their child with disability. One parent who discussed relationships with her child said, “I use examples of actors and actresses to explain about relationships”. Another parent who did not discuss these issues said “No, since my child has a disability, I do not share anything about relationship, love, sex or marriage. I only discuss domestic relationships such as father, mother, husband, wife, brother and sister”.

Anecdotal example: A girl with Mental Retardation had gone for a check up to a doctor’s clinic. The parents were illiterate. They were always made to stand outside the room during the check-up. The doctor would make the girl discard her clothes completely even when not required. The parents naively believed that the doctor did it for the check-up. There was no sexual assault in a strictly technical sense, but the girl was definitely sexually harassed as she was made to lie naked unnecessarily on the bed of the doctor’s clinic.

Issues concerning safety and violence were discussed by 63% parents with their child with disability. Majority i.e., 93% of the parents were aware that their child with disability also underwent bodily changes as they grew up and had physical and emotional requirements just like their able bodied child. Furthermore, 76% of the parents reported observing their child with disability looking at the mirror for long durations and smiling or giggling at self. More than half of the respondents (51%) did not want to respond to this question. Of the remaining (20 respondents) who did respond, 40% of the parents discussed “the incident of seeing their child exploring themselves” with their child, while 25% scolded the child. (Not shown). A little over half, i.e. 51% of the parents have not witnessed their child exploring/touching themselves.
Anecdotal example: An 8 year old female child with Down Syndrome has the habit of sitting with her legs wide open. She touches her inner thighs with the wooden support in the middle of the chair. Her father was informed about the act. It was noticed that she used to do that at home as well. Later, it was stopped, probably through training at home.

78% of the parents shared that their disabled child required assistance in personal tasks like bathing, dressing up, and among girls with changing sanitary napkins. About 12% parents shared that their child had complained of another person touching them inappropriately. 88% did not respond when asked "how did they react when their child complained about another person touching them inappropriately". Of the 5 respondents, 60% got angry with their child, 1 person consoled their child and confronted the culprit, and the remaining 1 person acted like it never happened because the person was a family member.

Anecdotal example: A boy would hug his mother excessively. He would also hug any girl or touch them without permission. The boy’s mother was informed and asked to rein in this habit of excessive hugging by her son. However the worried mother has been unable to check the child in this regard.

5.3 Discussion

As a parent, it is a palpable hope that their child will always make good choices that are based on the values that the family shares. An important part of discussing sexuality and sexual health with children is sharing with them what holds true for the parent as well. Parents are an extremely important part of a child’s life.

Every parent wants to provide the guidance and knowledge their children would need to become safe and happy adults. They take their responsibility for keeping their children safe from physical and emotional harm very seriously. However, parents are sometimes uncertain when it comes to discussing sexuality with their children because:

- They are uncomfortable talking about reproductive body parts and functions.
- For most parents, the topic of sex was not discussed with them and if at all discussed, it was when they became adults.
• They fear that talking about sexuality and reproduction will encourage their children to experiment.

The fact is people with disabilities whose parents and caregivers discuss all aspects of sexuality with them, are better prepared to protect themselves from abuse and make decisions about how to express their own sexuality. Most caregivers are not sure what children, teens or adults need to know. A common myth is that children and teens with developmental disabilities do not need to learn anything about sexuality because they will not develop into sexually mature adults. The truth is that all children are sexual beings from the beginning and will continue to develop socially and sexually throughout their lives. Caregivers are unsure about how to adapt the information to fit their child’s cognitive level.

Young people usually find out about sex from their parents, sex education programs in school, and from their friends - not necessarily in that order. The accuracy and depth of information shared depends heavily on the knowledge, experience, and comfort level of the provider. It should be no different for people with disabilities. Unfortunately, myths about people with disabilities and sex abound. One view is that people with disabilities are either not interested in sex or are not capable. At the other end of the spectrum, people with
disabilities are sometimes viewed as being overly interested in sex and incapable of controlling their sexual behaviour. Accurate information, free of stereotypical perceptions, must be available to each person who is disabled so that he/she can develop a healthy view of who he/she is as a sexual being.

The issue of protection is also a critical component of sexuality related information for people with disabilities; because people who are disabled are often vulnerable to sexual abuse and allowing myth to take over reason could also mean unnecessary exposure to sexually transmitted diseases. Access to accurate sexuality related information is crucial and very important for people with disabilities, their parents, teachers, caregivers, and others who may provide information. There is too much at stake to depend on misinformation in this area.
CHAPTER 6

TEACHERS’ PERCEPTIONS

6.1 Teachers’ perceptions of Sexual Health and Sexual Rights of Youth with Disabilities

When working with children and youth with disabilities, teachers/special educators can accomplish a great deal by managing the learning environment proactively to prevent behavioural problems and promote learning. But students with disabilities may also experience learning problems if teachers lack the skills and capacities required to work along with a child with disability. For a classroom dealing with students who have special needs - either physical, educational, emotional, or a combination of all three, teachers might find themselves searching for information and resources that will help effectively teach special students and help them learn successfully.

6.2 Profile

In order to understand the role of teachers/special educators with regard to sexuality, sexual health and relationships, a sample of 27 teachers across four study centres were selected for interviews. About 56% teachers were women; 12 teachers had studied up to 12th standard an equal number of them were graduates. All of them had completed a certificate course on disability, special needs, Braille or sign language, depending upon the YwD that they were, or would be working with. In short, all the 27 teachers had some training to handle youth with special needs.

6.3 Workplace experience of teachers

Among the teachers interviewed, 9 worked with children across different disability (ID, CP, VI, HI & ASD). The rest (18 teachers) worked with only one disability category. Most teachers (24) had seen or noticed the children exploring their bodies. This was found prevalent across age groups. About 42% children/youth within the age group of 17-19 were seen exploring their bodies followed by 30% children aged 19-25 years. 19 of those teachers who had
observed this behaviour among YwD discussed it with either colleagues or parents of the child or both. 10 teachers shared that they directly confronted the YwDs after observing them exploring their bodies. However they did confess that they were not sufficiently trained to appropriately handle such situations. They also went on to share that some YwDs (especially those with ID) do have aggressive behavioural problems. Handling children on a daily basis itself is such a challenging task that discussing topics around sexuality and relationships etc seemed to be yet another additional burden which they were themselves totally unprepared for. To add to this, they claimed a lack of cooperation from the parents of YwD.

Anecdotal example: There were about 18 residents living at the Sanjivani Hostel for youth with disabilities. Komal (name changed), 18 years of age, living in the hostel, was often seen holding his penis and on seeing others observing him, he would shy away. At night he was often observed lying face down on his bed and rubbing his penis on the bed. He even had frequent night falls. Even though such incidents occurred on a regular basis, there was no way that the authorities could discuss the observations with Komal or his guardians. There was a complete impasse to the matter.

6.4 Attitude of teachers towards sex and sexuality concerning YwDs

In an attempt to understand teachers' attitudes towards issues surrounding sex, sexuality, attraction and relationships, the participants were asked a series of questions using a three-point Lykart scale: Agree/Unsure/Disagree. The table below gives the scores against each of these statements, depicting teachers' perceptions on these topics concerning YwD. (Table 4.1)
Table 4.1: Statements depicting teachers’ attitudes towards sex and sexuality concerning YwD (N=27)

<table>
<thead>
<tr>
<th>Statements</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men and women with disabilities do not need sex</td>
<td>3.7</td>
<td>14.8</td>
<td>81.5</td>
</tr>
<tr>
<td>Men and women with disabilities are not sexually attractive</td>
<td>3.7</td>
<td>0</td>
<td>96.3</td>
</tr>
<tr>
<td>Men and women with disabilities are over-sexed</td>
<td>33.0</td>
<td>22.0</td>
<td>45.0</td>
</tr>
<tr>
<td>People with disabilities have other important needs than sex</td>
<td>81.5</td>
<td>3.7</td>
<td>14.8</td>
</tr>
<tr>
<td>Sex must be spontaneous</td>
<td>66.7</td>
<td>33.3</td>
<td>0</td>
</tr>
<tr>
<td>Women with disability should not have children</td>
<td>22.2</td>
<td>7.4</td>
<td>70.4</td>
</tr>
<tr>
<td>Girls and boys with disability should not have sex education</td>
<td>3.7</td>
<td>0.0</td>
<td>96.3</td>
</tr>
<tr>
<td>Girls can get pregnant by kissing and hugging</td>
<td>3.7</td>
<td>0.0</td>
<td>96.3</td>
</tr>
<tr>
<td>Men and women with disability have difficulty indulging in sex because of their disabilities</td>
<td>33.3</td>
<td>14.8</td>
<td>51.9</td>
</tr>
</tbody>
</table>

It is heartening to note that most teachers did not perceive the needs of the youth with disability to be any different from that of non-disabled youth. This is indicated by the scores that depict disagreement with statements that imply YwDs do not have or are not keen on sex. However one in three did agree that men and women with disability may have difficulty indulging in sex due to their disabilities. Six teachers felt that women with disabilities should not bear children.

Anecdotal example: In the same hostel (Sanjivani) lived Malini (name changed) who was 15 years of age. Many a times, Malini was seen rubbing her breast
against the person sitting next to her, whether a boy or girl. Once she even rubbed herself against the superintendent of the hostel, who was a lady. Care-takers at the hostel often resented her for putting her fingers and other objects into her vagina.

Furthermore, teachers were asked about their comfort levels while discussing about issues related to knowing one’s body, relationships, attraction, crushes, health and hygiene and violence with YwDs directly. Most of the teachers (23) said they felt extremely or fairly uncomfortable while discussing such issues with YwDs. Four teachers said that they were indifferent to these needs of YwD and did not discuss them at all.

6.5 Comprehensive sexuality education (CSE) in institutions working with YwD

Teachers were asked to share their institutes’ stand as far as sexuality education is concerned. Of the 27 teachers interviewed, only 7 reported that sex education is a part of their curriculum. However, only 6 of them disclosed that their institute makes an attempt to introduce YwD to these topics. Except for one teacher, the rest agreed that sex education should be included as part of the curriculum and that it was very important for YwD to be exposed to such topics. (Table 4.2)

Table 4.2: Teachers’ reports of CSE inclusion in institute curriculum (N=27) [Only Yes responses]

<table>
<thead>
<tr>
<th>Description</th>
<th>N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex education is part of their curriculum</td>
<td>7 (25.9)</td>
</tr>
<tr>
<td>School does make sex education accessible for YwDs</td>
<td>6 (22.2)</td>
</tr>
<tr>
<td>Sex education should be included as part of their curriculum</td>
<td>26 (96.3)</td>
</tr>
</tbody>
</table>

6.6 Discussion

Young people with cognitive, intellectual and developmental disabilities face many obstacles to healthy sexuality, including lack of education, vulnerability to sexually transmitted infections and pregnancy, and discrimination from a culture that has difficulty accepting these individuals’ sexual expression. Youngsters with special needs face a number of cultural barriers to healthy
sexuality and are commonly disadvantaged by a lack of appropriate sex education. On the other hand, charged with the responsibility of preparing children for the eventuality of adulthood, parents and educators face many challenges. Providing comprehensive human sexuality education to children, teens, youth and young adults with special needs is a particularly important but often formidable task. Like all children, students with disabilities grow into adolescence with physically maturing bodies and a host of emerging social and sexual feelings and needs. Before these changes begin and throughout adolescence, it is vital that educators and parents provide information in a positive and constructive way that is both clear and educationally appropriate. In this regard, teachers and caregivers play an important role in the development of young people with disabilities, including sexual health issues. It is not only parents but also teachers and educators who are in the circle of knowledge sharing and trust. What teachers say and do can have a major influence on the development of a child into a social being and this holds true even for children and youth with disabilities.

While most teachers interviewed agree that sex and sexuality issues must be part of the regular curriculum in their institution, most are not comfortable discussing it with the youth. In fact, 3.7% of teachers did not even know how women get pregnant.

Photo description: YwD at Shishu Sarothi
This means that their own understanding of sexual and reproductive process is flawed. There is therefore an urgent need to revamp and re-look at the teacher-training curriculum and include topics beyond academics. Sensitization of teachers to these topics and equipping them with skills to communicate and discuss these matters with the youth with disability should be given prominence during their training. While most special educators are trained to work with youth with disabilities, and may even learn about vocational training, they do not have holistic training in adolescent and adult issues. In view of such a scenario, this study recommends training for teachers and special educators on these topics.
CHAPTER 7

STRATEGIC COMMUNICATION MESSAGES

7.1 Key Communication messages

This chapter focuses on the findings that emerged from this qualitative research study, which could potentially feed into a strategy for communicating with YwDs. The findings bring out the gaps in the understanding of SHSR issues among teachers, parents and youth themselves, and point towards recommendations, for each of the issues identified.

7.2 Youth

- All YwDs participating in the study reported being attracted to the opposite sex, whether girls or boys, but were confused and did not know how to handle it. One limitation of this study is that it did not specifically discuss same sex attraction and therefore we are assuming heteronormativity in this response.

- It is clear from the qualitative data analysis that ‘growing up’ issues of the YwD need immediate attention and should be addressed in a way that they learn to deal with them in a more private way. YwDs require more information on safe touch and unsafe touch.

- Since the YwDs spend all their time between home and institute, there is a need to sensitize both teachers/special educators and parents as they are an integral part of a YwD’s life.

- From all the responses analyzed, it was evident that there is an inhibition associated with such issues and that they need to be handled with a friendlier and more sensitive approach.

- Specific training modules for teachers on sexual health, sexuality and integrated topics need to be developed. Also, a special manual for “communicating with YwDs on sexual and reproductive health issues” needs to be added to the training module. “I need my teacher to help me in understanding my ‘growing up’ issues” said Nilima (name changed) a boy with a
hearing impairment Jorhat.

- Certain specific quotes from some respondent youth are as follows:

  "I feel our limitation makes people laugh at us. I want our development, want people to understand us."

  "Except for our lack of vision everything is same like able bodied people. People should not laugh at us due to our disability because we all are equal."

  "I feel we are not different after all. We are all human beings. I want to do a job in future and earn for myself."

  "Both men and women are different and their hormonal change makes them more sexually active. So it is essential to give them knowledge on it. Socialization process is the main reason for our limitations."

  "I feel it is essential to impart knowledge on sex education for severe ID cases."

  "It is necessary to teach girls about safety, safe touch and unsafe touch."

  "I feel it is essential to develop academic side rather than other side because it helps us to learn."

  "I have learnt lots from the internet. I love to travel and talk with friends on different topics."

  "I like my caregiver because she loves me a lot, more than others. She helps me during periods. She helps me to dress up."

Clearly these quotes portray a dearly felt need among YwD. While for some, information about how to remain safe (the safe/unsafe touch education, limits of socialization) is important, others, prefer to learn a skill or develop academically to stand on their own feet. However, all agreed that discussions on these sensitive issues are important and information should be disseminated to them mostly at the institution through their care givers, who are more compassionate towards YwDs.

7.3 Parents

- Discussions on sexuality and relationships are low in priority among most parents. They do not feel comfortable discussing these issues with their wardz. Talking about sex and love, is related to acceptance of both oneself
and by significant others, which in turn forces them to confront ‘not so comfortable’ issues. This an added burden on the already isolated and laden lives of most YwDs

- Parents raised the issue of safety for their daughters with disability. It is in fact a priority for the parents to protect their children who have disabilities.

- Some parents are also concerned that if YwDs are taught to understand their growing up issues, and learn to express their sexuality, they could be led towards ‘wrong’ paths.

- Parents did not feel it necessary to discuss these issues with their children with disability, since they never felt the need to do so even with their able bodied children.

- Parents acknowledged that they never felt it was important to discuss growing up stages of YwD. They never needed to train their non-disabled children on these issues and therefore did not think it necessary to train their children with disabilities either.

- Parents also shared the need for sensitizing and creating awareness for an inclusive environment amongst local people to be more sensitive and empathetic towards YwDs.

- Finally, it is important to position dialogues around reproductive and sexual rights of YwD.

Findings based on reactions of parents to key issues:

Issue: Discussions about relationships, love, attractions, crushes and marriage

Overall findings: None of the parents in Tezpur reported discussing such ‘sensitive’ issues with their YwD. However in the other centres, many parents, mainly mothers, did discuss topics related to relationship, attraction and love with their wards. While some took the example of movies as a starting point, others were more direct in their communication. However, all did say that it was not easy for them to talk to their wards about these issues and that it would be better if it is initiated by an outsider or maybe in the school/institute. Many just restricted the discussion around family relationship, not going into the
attraction, crush and marriage issue. A few did mention the prospect of marriage with their wards to encourage them to start acting and behaving more responsibly.

**Recommendations:** Specific, simple and clear modules on each of these topics relationship (all kinds of relationships), love (all kinds of love parental, sibling, couple, etc.), attraction, crush and marriage can be developed. They could cite real life examples and make it more interactive. Using more pictures / audio teaching materials rather than written words will make it is easy to comprehend both by the parents at home and the teachers/special educators at the school/institute.

**Issue: Discussions about health and hygiene**

**Overall findings:** Most parents found it easier to discuss hygiene issues with their wards. It essentially revolved around physical hygiene, (bathing regularly, washing hands and private parts and keeping them clean at all times, keeping nails clipped and clean). Adolescent girls have been specifically told about menstrual hygiene by their mothers.

**Recommendations:** General health and hygiene are areas where most parents (except those from Tezpur) have been communicating rather easily and regularly with their children with disability. More specific discussions on sexual health and hygiene could be incorporated in the communication material being developed for parents, specific to the needs of the YwD.

**Issue: Discussion about violence and safety**

**Overall findings:** Parents of MR children with Intellectual Disability find it hardest to communicate safety issues to their children. They have cited feeling a sense of hopelessness since it was hard enough for them to struggle and cope with child care in the first place. To deal with such difficult issues like violence is very traumatic for parents to handle. However, parents of children with other disabilities (hearing and visual impairments,, autism) did report discussing safety issues with their children, especially concerning any sexual connotation to people’s behaviours like touching their private parts, making sexual gestures, kissing them etc.
5.3 Teachers

- All the teachers agree that there is definitely a need to create spaces for discussing issues of growing up and YwDs. They acknowledged that they themselves are not adequately equipped to handle these matters with YwDs in the most effective manner and they needed comprehensive training to address this issue appropriately. Almost all the teachers emphasized training YwDs on the concept of private and public.

- All the respondent teachers have agreed that the most convenient way to start the discussion around sexuality is to include the topic as part of the education curriculum, as it makes them comfortable to create the environment of learning and also to establish its necessity before the families.

- Teachers in a couple of cases also suggested that there is an urgent need to create learning spaces for the developmentally challenged YwDs in managing their sexual urges.

Findings based on reactions of teachers to key issues:

**Issue: What are the challenges of your job**

**Overall findings:** One of the challenges faced by teachers was getting the YwD to focus and concentrate on one subject. They also spoke of some students (ID/ASD) who get violent or may have sudden mood swings and how they felt at a loss to handle such instances. Many teachers reported lack of support from parents or caregivers, which made their work all the more difficult. There is little training and time for explaining to the students about how to take care of themselves. The teacher: student ratio is also very low. Overall, teachers find it difficult to work with children with impairments.

**Recommendations:** Training modules on teaching children with special needs should be considered. Teachers need more sessions on working closely with children with different disabilities, to handle their moods, to control their violent streak/temper (if any). Maintaining proper teacher: student ratio would allow teachers to spend sufficient time with each ward, and monitor them for essential outcomes.

**Issue: How do you manage it?**

**Overall findings:** Some suggestions from the teachers themselves on how they
have handled difficult / challenging situations are cited.

**Recommendations:** Some of these good practices being implemented by teachers can be discussed during teacher training and in a comprehensive module or compendium on “how to handle different challenges” that can be brought out as a ready reference for all teachers interacting with YwD.

**Issue:** What are the growing up issues of young boys with disability (Age group 15-25 years)?

**Overall findings:** Teachers claim that these issues were never part of their training and therefore they are unsure of how to handle situations such as those cited.

Most teachers complained of lack of parental involvement or support in their endeavour to help YwD especially those in their puberty and growing up stages. The most challenged are those teachers who work with ID and severely autistic children.

**Recommendations:** Teacher’s training modules should have separate specific sections on handling YwD’s sexual behaviour and health issues. This should be disability and gender specific. Parental orientation on how to handle young (15-25 years) boys and girls with disabilities, especially those concerning sexual arousals, is most vital.

**Issue:** What is the growing up issue of young girls with disability (age 15-25 yrs)?

**Overall findings:** Lack of orientation of teachers in understanding the growing up issues of young girls.

**Recommendations:** Teacher’s training module should have an entire section on handling YwD’s growing up issues, sexual behaviour and health issues and this should be disability and gender specific.

**Issue:** How do you manage it?

**Overall findings:** Teachers have been dealing with these issues on their own. These are all actions and measures developed through experience.

**Recommendations:** All these strategies worked out by the teachers need to be formalized and compiled into a training curriculum during their teacher train-
ing course. Currently subjects related to sexuality, sexual health and sexual behaviour is not part of their training curriculum.

**Issue: How do you react when you see young people with disabilities exploring their bodies**

**Overall findings:** Teachers lack skills and orientation and it was also observed that there is a lack of rationality in dealing with such situations.

**Recommendations:** Teacher’s training modules should have an entire section on handling YwD’s growing up issues, sexual behaviour and health issues. This should be for each of the types of disability and separate for boys and girls.

**Issue: If discussed with parents, how did the parent(s) react?**

**Overall findings:** There is a clear lack of acceptance and ignorance

**Recommendations:** It is absolutely essential to have parent-teacher collaboration in supporting YwDs at various stages of their lives, especially during their adolescence and post-puberty. Teachers cite lack of understanding on the part of some parents when behavioural issues pertaining to their wards are discussed. Therefore more engagement of parents in the lives of their wards is of utmost importance.

**Issue: How have the teachers made sex education accessible for youth with disabilities?**

**Overall findings:** There is a discomfort among teachers to talk about sex. They lack orientation and skills. Sex education only restricted to personal hygiene and touch.

**Recommendations:** Develop clear cut strategies in order to impart sex education. Develop training modules to make discussion on the subject, comfortable and simple.
CHAPTER 8

CONCLUSION AND RECOMMENDATIONS

The study has brought out some key recommendations which could help in developing communication material for youth with disabilities.

1. Sensitizing people who interact with youth with disability: Common misconceptions and stereotypes continue to be associated with sexuality and people with disabilities. For example, the belief that people with disabilities are either not interested in sex or unable to function sexually, and that they are somewhat innocent in sexual matters. Youth with disabilities are often portrayed as childlike, dependent and in need of protection. However, clearly, youth with disabilities experience similar or even higher levels of sexual anxieties as compared to their able bodied peers. “Boys have frequent sexual arousal and this does not mean that they should misbehave or use force on us girls!” (19 year old female participant with Cerebral Palsy, Guwahati)

2. Absence of adequate and timely information on sex, sexuality and sexual health: Youth with disabilities clearly spoke of the lack of information about sex, sexuality and sexual health. However, most reported that they like talking about relationships, marriage, crush, and relationship. As many as 50% of them have also reported discussing their feelings with people who they get attracted to. Several boys and girls across reiterated the need for more in-depth information, more discussions on these topics, and also getting parents involved in such discussions. Thus, there is a clear and urgent need for including comprehensive sexuality education in the institution curriculum for 15+ year old YwD. Separate sessions for parents and caregivers on how to approach such topics with the youth should also be conducted.

3. Gaps in teacher training: Teachers are not comfortable discussing such sensitive issues. Also, they do not know how to handle situations of youth observing themselves, touching their private parts in public, staring at the opposite sex, or any such behaviour that teachers feel is ‘not usual’. Teachers’ training should include a module on such sensitization.
4. Awareness about abusive behaviour and touch among YwD: Home is the place where most YwDs spent their time. Also, most of the perpetrators are people known to the survivor/abused. It becomes very important to discuss with YwDs about the difference between good and bad touch/behaviour, signs that these young people need to be wary of, the need to complain to their confidant (mostly mother) if at all they experience abuse in any form, however insignificant. Relevant communication aids need to be developed for ease of information dissemination among the youth at the institutions. Parents too need to be wary of and should be trained to handle similar situations in the home front. Some non-disabled people fear that if they have a relationship with a person with disability, they will ultimately become a caregiver rather than a partner. Another prevailing belief is that individuals with disabilities prefer to have relationships with other such people (Esmail, Darry, Walter & Knupp, 2010). These stereotypes and assumptions promote a negative view of people with disabilities that young persons with disability may internalize and accept. For able-bodied youth this may lead to a tendency to ignore or reject those with disabilities, and for youth with disabilities, this may result in low self-esteem and lack of sexual confidence.

Most parents and teachers support the right of youth with disabilities to have access to sex information and education although some also indicated that since their children were socially isolated and did not interact with peers, sex education was neither a necessity nor a priority. This is also highlighted in a study (East & Orchard, 2013b).

Some clear recommendations for communication material included integrating images of youth with disabilities, providing information in large print and plain text, presenting safe sex information relevant to youth with various disabilities, and developing websites specifically for YwD and widely disseminating them among the target audience. There is a need to also have interactive education that takes into account the unique needs of the individual, rather than general information designed for a broad audience. Information aimed at youth must also acknowledge how society excludes and marginalizes those with disabilities, and how these negative attitudes affect the development of sexual self-confidence and assertiveness.
What is the ‘take home’ message?

There are many negative stereotypes and assumptions associated with sexuality and disability. It is particularly challenging for youth with disabilities to develop a healthy sexuality in the face of such barriers. Youth with disabilities are often assumed to be childlike, naïve and lacking in sexual desire. As a result of these assumptions, healthcare professionals, caregivers and family members may feel uncomfortable talking about sexuality-related issues with youth with physical and intellectual impairments. All young people deserve access to good quality sexual health information and education regardless of physical and intellectual capabilities. Youth with physical impairments have the same desires for intimacy, relationships and sexual experiences as do their able-bodied peers. Sexual health information and education for youth should be inclusive of those with physical impairments and also provide information specific to the needs of Youth across all disabilities.

Most of the YwDs are considered objects of care, and as people one has to be ‘nice’ to. YwD are often seen as sick. Sick individuals are not expected to have a regular life with social responsibilities such as work. People with disability face enormous problems in getting employment (as discussed with employment division of Shishu Sarathi). No wonder that so many of them have low self-confidence. Without self-confidence it is difficult to see oneself as an attractive sexual being.

Those who need assistance in their daily lives with such tasks as getting dressed, washed, going to the toilet, or in case of girls, changing sanitary napkins are most exposed to the protective attitudes of our surroundings. The physical dependence on others is automatically equated with intellectual and emotional dependence. A person who feels inferior will not be able to establish a sound relationship with another person that is based on equality.
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Annexure 1

A study to understanding YwDs exposure to issues related with building relationships, understanding their bodies, knowing more about their own health & hygiene and learn about violence and safety

Name of the Investigator: .................................................................

Date of interview: ............................................................................

Semi-structured questionnaire for Youth

Method- One to One Discussion

Age Group- 15-25 years

A. Socio-economic and family information

A1. Sex of the respondent (Do not ask)
   1. Male
   2. Female

A2. What is the kind/nature of Disability (Do not Ask):
   1. ID
   2. CP
   3. VI
   4. HI
   5. ASD
   6. Others (Specify)..............................(Report as responded)

A3. What is the extent/degree of Disability (Do not ask):
   1. Low or Marginal Degree of Disability
   2. High Degree of Disability

A4. How old are you? (INS: report completed years): _______ years
A5. What is your Religion?
   1. Hindu
   2. Muslim
   3. Sikh
   4. Christian
   8. Other (specify)

A6. Have you ever attended Special or Regular school? INS: If 'No' skip to A8
   1. Yes  Formal School
   2. Yes- Informal School
   3. No- (No School Attended)  (Skip to A8)

A7. For how long have you attended this school? (no. of years of schooling)
   ________ Years

A8. Are you currently attending one of the schools as listed below? (Tick whichever is appropriate)

<table>
<thead>
<tr>
<th>Informal School</th>
<th>Regular School</th>
<th>Special School</th>
</tr>
</thead>
<tbody>
<tr>
<td>At Home</td>
<td>Only Boys</td>
<td>Only Boys</td>
</tr>
<tr>
<td>Group Study</td>
<td>Only Girls</td>
<td>Only Girls</td>
</tr>
<tr>
<td>Other (specify)</td>
<td>Co-educational school</td>
<td>Co-educational school</td>
</tr>
</tbody>
</table>

INS: A9- A11 ask only if respondent is 18-25 years

A9. Are you currently working? (Paid work)
   1. Yes
   2. No
   3. Not applicable (INS: If not within age group)
A10. If Yes in A9, what work do you currently do? (Report as mentioned)

A11. How much do you earn in a month?
   1. <5000
   2. 5000-10000
   3. 10000+

A12. How many people are there in your family? INS: Actual no’s reported

A13. What do you usually do in your free time? (Hint: Probe Question)
   INS: Only One response
   1. Going to a neighbour
   2. Going to a relative’s house
   3. Going to the market
   4. Playing a Game
   5. Doing homework together
   6. Other (specify)...............................(Report as mentioned)

A14. With whom do you usually spend your free time with?
   1. Father
   2. Mother
   3. Siblings
   4. Friends/relatives
   5. Caregiver
   8. Other (specify).................................(Report as mentioned)

A15. With whom are you most comfortable to discuss or talk about your health issues or growing up issues or personal issues? (INS: ONLY ONE RESPONSE)
   1. Father
   2. Mother
3. Older sibling
4. Friends
5. Doctor
6. School Teacher
7. Care-giver
8. Others (specify)............................... (Report as mentioned)

B Access to communication mediums

B1. Do you watch movies/TV shows/other programmes (show cards depicting different kind of TV shows)

<table>
<thead>
<tr>
<th>A. Type of programs</th>
<th>B.</th>
<th>C. How many times during the last week did you watch reported shows/programs? (No. of times)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Movies</td>
</tr>
<tr>
<td>1</td>
<td>No</td>
<td>TV serials</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>News</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sports</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cartoons</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wildlife</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other (specify)</td>
</tr>
</tbody>
</table>

B2. Do you have access to internet?
   1 Yes
   2 No (Skip to B4)

B3. If yes in B2, what are the top three sites that you normally visit on the internet?
(Probe for responses)

1.

2.

3.

B4. Do you own a mobile phone?
   1. Yes
   2. No (skip to section C)

B5. What do you use the Mobile phone most for? (Show cards) [Only one response]
   1. Calling up friends
   2. Calling up family
   3. Messaging
   4. Health advice
   5. Playing games
   6. Accessing internet
   7. Click Pictures and listen to Music
   8. Other (specify)

C. Learning about our Bodies

INS: Show a picture of a male and a female body in different growing stages and ask the questions below. (SHOW CARD)

C1. As you are growing up, do you feel/notice any change happening to your body?  
   (Probe- For Girls-body growing rounder or fuller, expansion of your hip, hair growth under your arms and other genitals, development of breasts and For Boys- change in voice amongst boys, hair growth on the chest, hands and legs, arms and genitals, begin to have sexual thoughts and urges)
   1. Yes
   2. No
   3. DK/ CS
   (Show the pictures and probe)
C2. Is it ok to explore your body parts?
   1. Yes
   2. No
   3. DK/CS

C3. Which parts of your body do you observe or are most curious about? (SHOW CARDS)

C4. Do you think that every human being undergoes bodily changes as they grow?
   1. Yes
   2. No
   3. DK/CS

C5. Do you feel happy when you see a certain person from the opposite sex/same sex? (Probe- May be your friend, some actor, celebrity)
   1. Yes
   2. No
   3. DK/CS

C6. Do you feel yourself getting attracted to that person as mentioned in C5?
   1. Yes
   2. No
   3. DK/CS

C7. Are these people (friends/actor/celebrity) whom you feel attracted towards, disabled or non-disabled?
   1. Disabled
   2. Not disabled

C8. Do you think girls and boys can be friends with each other?
   1. Yes
   2. No
   3. DK/CS
C9. Is it alright for a disabled person to have girlfriends or boyfriends?
   1. Yes
   2. No
   3. DK/CS

C10. Is it normal for a disabled person to discuss about growing up issues? (Probe for further response)
   1. Yes
   2. No

C11. How comfortable are you discussing these growing up issues? (Probe for further response)
   1. Comfortable
   2. Uncomfortable

(IN5: Questions C12-16 for respondents aged 18-25 years)

C12. Have you heard of the word 'Sex'?
   1. Yes
   2. No

C13. Do you think a disabled person can indulge in Sex?
   1. Yes
   2. No
   3. DK/CS

C14. A non-disabled person will be alright having sex with a disabled person
   1. Agree
   2. Disagree
   3. Not sure

C15. If a disabled girl/boy wants to have sex, he/she will be termed as a bad person. Do you agree or disagree or are not sure of this statement?
   1. Agree
   2. Disagree
   3. Not Sure
C16. Do you think a person (boy/girl) can force another person (boy/girl) to have sex with (him/her)?
   1. Yes
   2. No
   3. DK/CS

C17. Do you think if a non-disabled person talks to you, it will be for one or more of the following reasons?
   1. Some help
   2. Friendship
   3. Harmful intention (Probe)
   4. Other (Specify)

D. More about Relationships, Health & Hygiene, and Education
   (INS: Explain what do you mean by growing up) As we all grow up, we learn about our bodies, the changes in our bodies, feelings like hugging someone, holding hands or even kissing. We may learn about these from teachers at school, from friends, from books & movies and so on.

D1. Do you like to make friends?
   1. Yes
   2. No

D2. How many friends do you have? (Report in number as shared)

D3. Do you have both disabled and non-disabled friends?
   1. Only Disabled Friends
   2. Only non-disabled friends
   3. Both disabled and non-disabled friends

D4. Do you like talking about love, attractions, crushes and marriage with someone?
   1. Like
   2. Dislike
   3. Not sure/can't say

D5. Have you ever discussed about your feelings on love, attractions, crushes and
marriage with anyone?
1. Yes
2. No (Skip to D7)

D6. With whom have you discussed about these feelings on love, attractions, crushes and marriage?
1. Parents
2. Teachers/caregivers
3. Friends
4. Relatives
5. Neighbour
6. Others (Specify) ..........................................
7. (Report as mentioned)

D7. Do you feel, because you are disabled, others might make fun of you when you talk about love, attraction, crushes and marriage?
1. Yes
2. No
3. Don't Know/Can't Say (INS: Questions D8-D14 to be asked to respondents aged 18-25 years)

D8. What does it mean to you when a girl and boy get together? (Add probing points: for example, does it mean that they are just friends, or are in love, or just like being in each other's company or does it meant that they will indulge in Sex)? INS: Report as responded

D9. Do you talk to anyone about feelings and desires related to sex? If so, with whom do you discuss?
1. Yes
2. No (If No, skip to D11)

D10. If yes in D9, with whom do you discuss it with? (INS: report as responded)

D11. Does sex mean marriage?
1. Yes
2. No

D12. Some institutes for disability have sessions related to sex education as part of
their course curriculum. Have you ever been exposed to any such session?
1. Yes
2. No
3. Not sure
4. Never been to such institution

D13. Do you think it is important to have such sessions on understanding your body, growing up issues, relationship, etc. in the institute?
1. Yes
2. No
3. Not sure

D14. Now I shall read to you some statements. Please indicate whether you agree or disagree or are not sure for each of the statements:

<table>
<thead>
<tr>
<th>Statements</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men and Women with disability do not need sex</td>
<td></td>
</tr>
<tr>
<td>Men and Women with disability are not sexually attractive</td>
<td></td>
</tr>
<tr>
<td>Men and Women with disability are over sexed</td>
<td></td>
</tr>
<tr>
<td>People with disability have other important needs than Sex</td>
<td></td>
</tr>
<tr>
<td>Sex must be spontaneous</td>
<td></td>
</tr>
<tr>
<td>Women with disability should not have children</td>
<td></td>
</tr>
<tr>
<td>Girls and boys with disability do not need sex education</td>
<td></td>
</tr>
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<td>A girl can get pregnant by kissing and hugging</td>
<td></td>
</tr>
<tr>
<td>Men and women with disability have difficulty indulging in sex because of their limitations</td>
<td></td>
</tr>
</tbody>
</table>
INS: D15-D26 for all age group

D15. How old were you when you had your first menstruation? (Age in completed years)

D16. Did you have any prior information about menstruation?
   1. Yes
   2. No

D17. If yes, who explained to you about menstrual periods and hygiene?
   1. Mother
   2. Care givers
   3. Other (specify)
   4. Not explained at all (If No in D16, it will be taken as 'Not explained at all')

D18. How do you manage your menstrual hygiene?
   1. Manage on my own
   2. Need help (INS: Ask who helps mostly and report as responded)

D19. If you need assistance, how do you feel about being assisted by someone else for your menstrual hygiene?
   1. Feel comfortable
   2. Feel dependent
   3. Feel embarrassed

D20. What do you use during your periods?
   1. Old cloth
   2. Locally prepared napkins
   3. Branded Sanitary napkins
   4. Nothing
   3. Other (specify)

D21-25 only for BOYS

D21. Did you have any prior information about bodily changes happening in your body (during puberty) (Probe for facial hair, pubic hair, body hair, and change
in the voice)?
1. Yes
2. No

D22. If yes in D19, with whom did you discuss about these changes?
1. Father
2. Mother
3. Care giver
4. Not explained at all
5. Others (Specify)………………………………... (Record as responded)

D23. How old were you when you first observed these body changes? (Age in completed years)

D24. Do you experience night falls?
1. Yes
2. No

D25. Have you discussed about night falls with anyone?
1. Yes
2. No

D26. Questions on pregnancy and contraception (for respondents over 18 years)

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know where babies come from?</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Have you ever discussed about how babies are born?</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Is it all right for boys and girls to have sex with each other provided that they use methods to prevent Pregnancy?</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Have you ever seen a condom?</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
</tbody>
</table>
| People have different opinions about condoms. I will read out some opinions. For each one, I want you to tell me whether you agree, disagree, or whether you don’t know/are not sure | 1. Agree  
2. Disagree  
3. Don’t know/not sure |
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Condoms are an effective method of preventing pregnancy</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Condoms are also meant for disabled boy/men</td>
<td>1 2 3</td>
</tr>
<tr>
<td>A condom can be used more than once</td>
<td>1 2 3</td>
</tr>
<tr>
<td>It would be too embarrassing for a disabled person to buy or obtain condom</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Condoms are an effective way of protecting against sexually transmitted diseases</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

**E. Knowing more about our Body and Violence**

E1. Have you ever heard of the word 'sexual violence'?
   1. Yes
   2. No

E2. Do you know what a safe touch is?
   1. Yes
   2. No

E3. Do you know what an unsafe touch is?
   1. Yes
   2. No

E4. Can you differentiate between a safe touch and an unsafe touch? (If the respondent is not able to respond, we can probe by asking if anyone has touched them on the chest, between legs or bottom (if girls), and between legs and bottom (if boys), for them to understand what bad touch is.)
   1. Yes
   2. No

E5. Has anybody ever touched you in a manner which has made you feel uncomfortable?
1. Yes
2. No   (If No, Skip to Section F)

E6. Where did the incident happen?
   1. At the institute
   2. At home
   3. Other (specify).................................(Report as responded)

E7. Did you know the person?
   1 Yes
   2 No
   3 Not sure

E8. Did you feel threatened?
   1 Yes
   2 No

E9. Did you discuss the incident with somebody?
   1 Yes
   2 No

E10. If yes, with whom did you discuss?
    1 Mother
    2 Father
    3 Teacher/caregiver
    8 Other (specify)

E11. How did this person react to what you shared?
    1. Ignored what you shared
    2. Made fun of it
    3. Calmly listened to you
    4. Advised you to share it with authorities
    5. Asked you to shut the matter

E12. On sharing it with higher authorities, was the accused punished?
1. Yes
2. No
3. Did not share with higher authorities at all

F. General

F1. How important is it to discuss issues around growing up, menstruation, sex, love, relationship, attractions, safe touch, unsafe touch, marriage and violence?
   1. Important
   2. Not important
   3. Not sure

F2. Who would you prefer coming and talking to you about issues around relationships, knowing your bodies, health and hygiene and violence?
   1. An unknown person / person from outside institute
   2. Mother
   3. Father
   4. Older siblings
   5. Teacher/caregiver
   6. Friends
   7. Others (specify)..................................................

F3. Is there anything else that you would want to discuss or suggest with regards to issues mentioned above?

THANK YOU VERY MUCH FOR YOUR TIME. WE TRULY APPRECIATE YOUR CO-OPERATION AND PATIENCE. PLEASE BE ASSURED THAT ALL YOUR RESPONSES WILL BE TOTALLY CONFIDENTIAL AND ANONYMOUS AND WILL BE USED ONLY FOR RESEARCH PURPOSE.

FST
Annexure 2

A study to understanding YwD's exposure to issues related with building relationships, understanding their bodies, knowing more about their own health & hygiene and learn about Violence and Safety

<table>
<thead>
<tr>
<th>Name of the interviewer</th>
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<tbody>
<tr>
<td>Date of interview</td>
</tr>
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<tr>
<td>Name of the Institution</td>
</tr>
</tbody>
</table>

Semi-structured questionnaire for Parents

Method- Indebt Qualitative Interview

A. Socio economic and family information

A1. Sex of the respondent (Do not ask):
   1. Male
   2. Female

A2. Age of the respondent (report age in completed years): _____ years

A3. Relationship with the disabled child
   1. Mother
   2. Father
   3. Other (specify)

A4. What is your level of education? (Mark the response in circle)
   1. Primary (1-4 years)
   2. Middle (5-7 years)
3. High School (8-10)
4. Sr. Secondary (11-12)
5. Graduate
6. Post-Graduate
7. Others (specify)

A5. What is your religion?
   1. Hindu
   2. Muslim
   3. Sikh
   4. Christian
   5. Other (Specify)

A6. What is your occupation? (INS: record as mentioned)

A7. How much is your monthly family income? (Instructions: add all sources of income)
   1. <Rs. 10,000
   2. Rs. 10,000-15,000
   3. Rs. 15,000-20,000
   4. Rs. 20,000 +

A8. How many children do you have?

A9. How old is your disabled child? (Age in completed years of the 'index' child):
   _______ years

A10. Sex of the child
   1. Male
   2. Female

A11. What disability does your child have? (Report exactly as mentioned)
A12. Does your child go to any special school?
   1. Yes
   2. No

B. Communication within family

B1. In a regular day, how much time do you spend on an average with your disabled child? (Report in hours. minutes)

B2. How do you spend time with your disabled child on a regular day? (Hint: Probe Question- Yesterday, what were the activities that you and your child did together?)
   [Multiple responses possible]
   1. Going to a neighbor
   2. Going to a relative's house
   3. Going to the market
   4. Playing a Game
   5. Doing home work together
   5. Other (specify)

C. Discussions around knowing and exploring your Body, Relationships, Health and Hygiene, Health Education and Violence

C1. Are you aware of the topics and issues around knowing your Body, Relationships, Health and Hygiene, Health Education?
   1. Yes
   2. No

C2. Have you ever discussed growing up issues with your able bodied child? (Probe: Like- Menstruation, Hygiene, Bodily changes, facial hair changes in boys, pubic hair, chest hair, how breast grows, increases in penis size, etc.)- Only if the parent has more than one child
   1. Yes
   2. No

C3. Have you ever discussed growing up issues with your disabled child? (Probe: Like- Menstruation, Hygiene, Bodily changes, facial hair changes in boys, pubic hair, chest hair, how breast grows, increases in penis size, etc.)
1. Yes
2. No

C4. Do you discuss about relationships, love, attractions, crushes and marriage with your Disabled child? (If Yes, Probe on what and how it is discussed)
   
   If yes, Probe on what and how it is discussed:
   
   1. Yes
   2. No

C5. Do you discuss about health and hygiene with your disabled child? (If Yes, Probe on what and how it is discussed)
   
   If yes, Probe on what and how it is discussed:
   
   1. Yes
   2. No
   
   If yes, Probe on what and how it is discussed:

C6. Do you discuss about violence and safety? (If Yes, Probe on what and how it is discussed)
   
   1. Yes
   2. No

C7. With your non-disabled child, do you discuss about choices one can make about their body and medical treatment? (If Yes, Probe on what and how it is discussed)
   
   If yes, Probe on what and how it is discussed:
   
   1. Yes
   2. No

C8. With your disabled child, do you discuss about choices one can make about their body and medical treatment? (If Yes, Probe on what and how it is discussed)
   
   If yes, Probe on what and how it is discussed:
   
   1. Yes
2. No

C9. Like any other non-disabled person, are you aware that a child with disability also undergoes bodily changes as they grow up and also have certain physical and emotional requirements?
   1. Yes
   2. No

C10. Have you ever seen your disabled child looking at the mirror for long duration and smiling or giggling at self?
   1. Yes
   2. No

C11. Have you ever seen your child exploring/touching themselves?
   1. Yes
   2. No

C12. How did you react to it? (Do not probe. Circle all responses that are mentioned)
   1. Did not know how to react
   2. Scolded the child
   3. Discussed with the child
   4. Discussed with spouse
   8. Other (specify)

C13. Did you discuss about these issues with anybody?
   1. Yes
   2. No

C14. Does your disabled child need assistance in personal task like bathing, dressing up, changing sanitary napkins (in case of a girl child)?
   1. Yes
   2. No

C15. During PTMs, has there been a discussion on topics around helping your disabled child understand his/her body, exploring their bodies, relationships, health and hygiene and violence and safety?
1. Yes
2. No

C16. Has your child ever complained of another person touching them inappropriately?
1. Yes
2. No

C17. If yes in C16, how did you react to it? Probe. INS: Record as mentioned

C18. Did you report it?
1. Yes
2. No

C19. Whom did you report it to? Probe. INS: Record as mentioned

C20. Is there anything else that you would want to discuss with regard to topics and issues discussed above? Are there any suggestions that you might have with regard to these topics or any other that you think is important to include in communication with your disabled child? INS: Give time to the respondent to speak and record as mentioned

THANK YOU VERY MUCH FOR YOUR TIME. WE TRULY APPRECIATE YOUR CO-OPERATION AND PATIENCE. PLEASE BE ASSURED THAT ALL YOUR RESPONSES WILL BE TOTALLY CONFIDENTIAL AND ANONYMOUS AND WILL BE USED ONLY FOR RESEARCH PURPOSE.
Annexure 3

A study to understanding YwD's exposure to issues related with building relationships, understanding their body, knowing more about their own health & hygiene and learn about Violence and Safety

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<td>Name of the Institution</td>
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</tr>
</tbody>
</table>

Semi-structured questionnaire for Teachers

Method- Indebt Qualitative Interviews

A. Background Information

A1. Sex of the respondent (Do not ask)
   1 Male
   2 Female

A2. Age of the respondent (in completed years): _____ years

A3. For how long have you been associated with this institute/ organization? (Mention as reported): _____ years.

A4. Level of Education:
   1. Primary
   2. Middle
   3. High schools
   4. Sr. Secondary
   5. Graduate
6. Post-Graduate
7. Other (specify)/ Technical/ special education

A5. What type of training have you attained? (Specify as reported) INS: Trainings with regard to occupation/ working with disabled children

A6. What was the duration of training? _____ Years

B. Work place experience

B1. As part of your work, do you interact with disabled students?
   1. Yes
   2. No

B2. If 'Yes' in B1, with which kinds of disability have you interacted? (List all that is reported)

B3. What are the challenges of your job? (Open ended; Probe; challenges one faces when taking care of YwDs)- INS: Record as reported in clear bulleted points

B5. How do you manage it? (Probe)- INS: Record as reported in clear bulleted points

B6. What are the growing-up issues of young disabled boys (age group 15-25 years)? INS: Record as reported in clear bulleted points

B7. What is the growing up issues of the young disabled girls (age 15-25 years)? INS: Record as reported in clear bulleted points

B8. How do you manage it? (Probe) INS: Record as reported in clear bulleted points

B9. Have you ever seen or heard young people exploring their bodies in your institute?
1. Yes
2. No

B10. Which age group of children do you find exploring their bodies?
1. 15-17
2. 17-19
3. 19-21
4. 21-25

B11. How do you react when you see young people exploring their bodies? Probe. INS: Record as reported in clear bulleted points

B12. Who do you discuss these issues with? (Multiple response circle whichever reported)
1. Nobody
2. Parents
3. Colleagues
4. Other (Specify).

B13. If discussed with parents, how did the parent(s) react? Probe. INS: Record as reported in clear bulleted points

B14. Have you at all discuss it with the young person concerned?
1. Yes
2. No

B15. What have you discussed? Probe. INS: Record as reported in clear bulleted points

B16. Have you come across any YwDs who has been sexually abused?
1. Yes
2. No (Skip to B18)

B17. How did you react to it? Probe. INS: Record as reported in clear bulleted
points

B18. Now I shall read to you some statements. Please indicate whether you agree or disagree or are not sure for each of the statements?

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<thead>
<tr>
<th>Statements</th>
<th>Responses</th>
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</tr>
<tr>
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</tr>
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</tr>
<tr>
<td>Men and women with disability have difficulty indulging in sex because of their limitations (or disability)</td>
<td></td>
</tr>
</tbody>
</table>

B19. How comfortable are you discussing issues related to knowing your bodies, relationship, love, attraction, crushes, health and hygiene and violence with YwDs?

1. Very Uncomfortable
2. Fairly uncomfortable
3. Indifferent

B20. Is sex education part of your school curriculum?

1. Yes
2. No (Skip to B24)
B21. Does your school make sex education accessible for youth with disabilities?
   1. Yes
   2. No (Skip to B24)

B22. How have they made sex education accessible for youth with disabilities? Probe.
    INS: Record as reported in clear bulleted points

B23. What are the topics included in the sex education curriculum? (List all topics stated)

B24. Do you think it is necessary to include sex education as a part of your school curriculum?
   1. Yes
   2. No

B25. Is there anything else that you would want to discuss with regard to topics and issues discussed above? Are there any suggestions that you might have with regard to these topics or any other that you think is important to include in communication with your disabled child? INS: Give time to the respondent to speak and record as mentioned

THANK YOU VERY MUCH FOR YOUR TIME. WE TRULY APPRECIATE YOUR CO-OPERATION AND PATIENCE. PLEASE BE ASSURED THAT ALL YOUR RESPONSES WILL BE TOTALLY CONFIDENTIAL AND ANONYMOUS AND WILL BE USED ONLY FOR RESEARCH PURPOSE.

FST
CBO Jorhat - Prerona

CBO Tezpur - Sanjiwani

CBO Mrinaljyoti

Shishu Sarothi
YwD at Sishu Sarothi

De-mystification workshop

YwD study participants during interview
Teachers at work

Developing materials for interview

Team of FST with investigators

Workshop at Sishu Sarothi
ABOUT US

National Foundation for India (NFI) is an independent grant making and fundraising foundation, with a core mandate to strengthen philanthropy in India for public welfare and social transformation. NFI has established the “Youth Innovation Fund” to support and facilitate innovations on issues related with reproductive and sexual health amongst youth in India. NFI has set up this fund with a focus on “innovations” to address the multiple and complex challenges of reproductive and sexual health intervention amongst young people through a small grants facility. There are eight partners of YIF working in 6 States of India and there are 4 research studies initiated to understand certain specific aspects of young people’s sexual reproductive health.

www.nfi.org.in

Foundation for Social Transformation-enabling north east india(FST), is an indigenous philanthropic organisation of North East India born in 2008. It was started by a group of likeminded citizens who believed that the north eastern states of India needed a grant making institution solely committed towards fostering positive change in the region. FST has a strong commitment towards peace building in the region through innovative and inclusive rights based solutions. FST works in 7 states of North East India, which are Assam, Arunachal Pradesh, Meghalaya, Mizoram, Manipur, Nagaland and Tripura.

www.fstindia.org

Shishu Sarothi was established in 1987 is a registered non-profit voluntary organization which has emerged as a premier Centre for Rehabilitation and Training for Multiple Disabilities in the North East region. ShishuSarothi is the first institution in Assam to cater specifically to the acute and special needs of children with developmental disabilities, encompassing services like early intervention, special education, counseling, information and communication technology lab, outreach programs, community based rehabilitation and various other programs providing all round development of children with disability. The primary aim of the Centre is the empowerment of children with disability by providing them avenues for holistic development in cognitive, physical and socio-emotional domains, leading to developing academic, self-help and functional skills.

www.shishusarothing.org

Photo Courtesy - Shishu Sarothi and FST