Creating 'Suvidha' - A Toolkit to Help Children with Intellectual Disability Learn Personal Safety and Sexuality Etiquette – a firsthand experience

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I. Introduction

According to a study by Tharinger, Horton and Millea[1] (1990) it was found that children, adolescents, and adults with intellectual disabilities (ID) are particularly vulnerable to sexual abuse and exploitation and are in need of intervention services.

In another study conducted by Sullivan and Knutson[2] (2000) it was found that children with intellectual disabilities were at slightly greater risk of sexual abuse than disabled children in general, who in turn were at 3.14 times greater risk of experiencing sexual abuse than non-disabled children.

According to a working paper by TARSHI[3] (2010), discussions around sexuality and disability focus on medical health and protection from abuse. Sexuality from a health perspective looks into prevention of infection or restoration of sexual functioning and the abuse perspective correctly considers the vulnerabilities of people with disabilities to sexual abuse at home, in institutions or elsewhere. Sexuality, however, comprises of more than just these two aspects and includes actual sexual practices, experiences, adaptive techniques and capabilities. The charity or welfare model of disability views the person with disabilities as the problem and dependent on the sympathy of others to provide assistance in a charity or welfare model. This is the philosophy of a number of disability organisations in India even today.

Children with special needs specific to intellectual disabilities are often regarded as innocent, infantile, asexual and incapable of decision making. They are also denied the right to privacy, right to set boundaries from touches and any information around sexuality and safety[3.] Indian parents and teachers, who by and large avoid discussing sexuality with neuro-typical children/adolescents may label children/adolescents with ID hyper-sexual and punish them for failing to deduce and conform to social norms.

According to a Ministry of Women and Child Development, Government of India survey of 12447 children (without disability) in 13 states (published 2007) 53.22% children reported having faced one or more forms of sexual abuse, 21.90% child respondents reported facing severe forms of

sexual abuse and 50% of abusers are persons known to the child or in a position of trust and responsibility. Most children did not report the matter to anyone.

Children and adolescents with intellectual disability are particularly easy targets due to several factors:

- Dependency on others for personal care
- Seeking affection due to lack of socialization
- Trusting others easily
- Passively obeying adults in authority
- Lack of knowledge and understanding about personal space and sexual safety
- Difficulty in communicating abuse

II. Review of literature

1. WHO and UNFPA (2009)[4] published a document that stated "like everyone else, persons with disabilities have sexual and reproductive health (SRH) needs throughout their lives, and these needs change over a lifetime. Different age groups face different challenges. For example, adolescents go through puberty and require information about the changes in their bodies and emotions, and about the choices they face concerning sexual and reproductive health related behaviour. Adolescents with disabilities need to know all this information, but they also may need special preparation concerning sexual abuse and violence and the right to protection from it. It is important to assure that SRH services are friendly to youth with disabilities."

2. Gillian Eastgate (2008)[5] conducted a study which revealed that beliefs persist in the community that people with intellectual disability are either childlike and asexual, or oversexed and likely to become sex offenders. They are likely not to be offered the full range of choices for contraception and sexual health screening.

3. TARSHI, a non-profit organisation in New Delhi through their study on Sexuality and Disability in the Indian context (2010)[3] found that sexuality education is yet to be included in the school curriculum. Those against introducing sexuality education in schools feel that it will encourage sexual experimentation among young people. Other opponents feel that it would lead to a 'moral decay of our culture'. It is no surprise then that sexuality education for children with disabilities is not being discussed at all. They also found that there is an abysmal dearth of sexual and reproductive health services for people with disabilities. There is a lack of first person accounts data and research available on people with intellectual disabilities and sexuality

4. Thomas Kishore (2009)[6] in his paper on 'Disability impact and coping in mothers of children with intellectual disabilities' stated a suggestion that interventions may also focus on equipping caregivers with specialized knowledge and strategies in addition to their

inherent coping resources (Glidden et al., 2006) but preferably within the context of culture (Goldbart and Mukherjee, 1999).

5. Renu Addlakha[8] (2007) in her paper on Gender, Subjectivity and Sexual Identity said pity, segregation, discrimination and stigmatisation became normalised in the management of persons with disabilities. Such constructions of the disabled by the non-disabled have the dual effect of not only justifying the complete marginalisation and disempowerment of a whole population group but also leading to the internalisation of such negative stereotypes by disabled persons themselves.

III. Methodology

Aim: As Enfold Proactive Health Trust has worked with over one lakh regular school going children from 1st to 12th grade in the last 15 years and has developed culturally appropriate modules on how to teach children Personal Safety and impart value based sexuality education; we now aim to develop similar material for use by caregivers of children with cognitive special needs (ID).

Objective:

1. To identify areas which require attention in imparting personal safety and value based sexuality education to children with ID.
2. To know whether teachers/trainers and parents/caregivers are equipped and comfortable to talk about personal safety and value based sexuality.
3. Develop 'Suvidha' – a toolkit to help children with intellectual disability learn personal safety and sexuality etiquette

A study was conducted for objective 1 and 2.

Study sample: 34 adults comprising of 22 teachers/trainers and 12 parents/caregivers working with children with ID in Bangalore and Raipur.

There was no distinction made between parents/caregivers and teachers/trainers while collecting responses as both need to work together with children (with ID) in order to bring about a desirable behaviour.

Procedure: A need assessment was carried out through a Google form as well as through directly administered forms in English and Hindi in Bengaluru and Raipur.

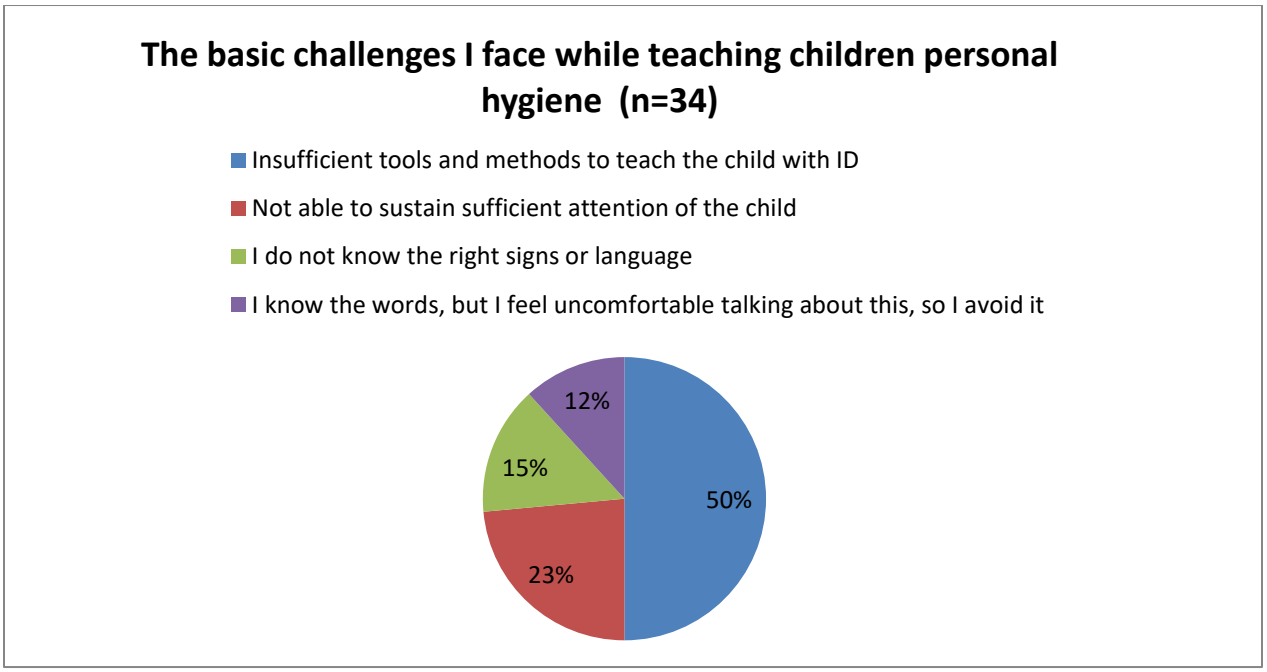
Analysis: Percentage of responses on each multiple choice question/statement was calculated. The results were later tabulated and their graphical representations were created.

Scale description: A questionnaire each for parents/caregivers and teachers/trainers was developed by Enfold in consultation with specialists working in the area of intellectual disability.

IV. Results and Discussion:

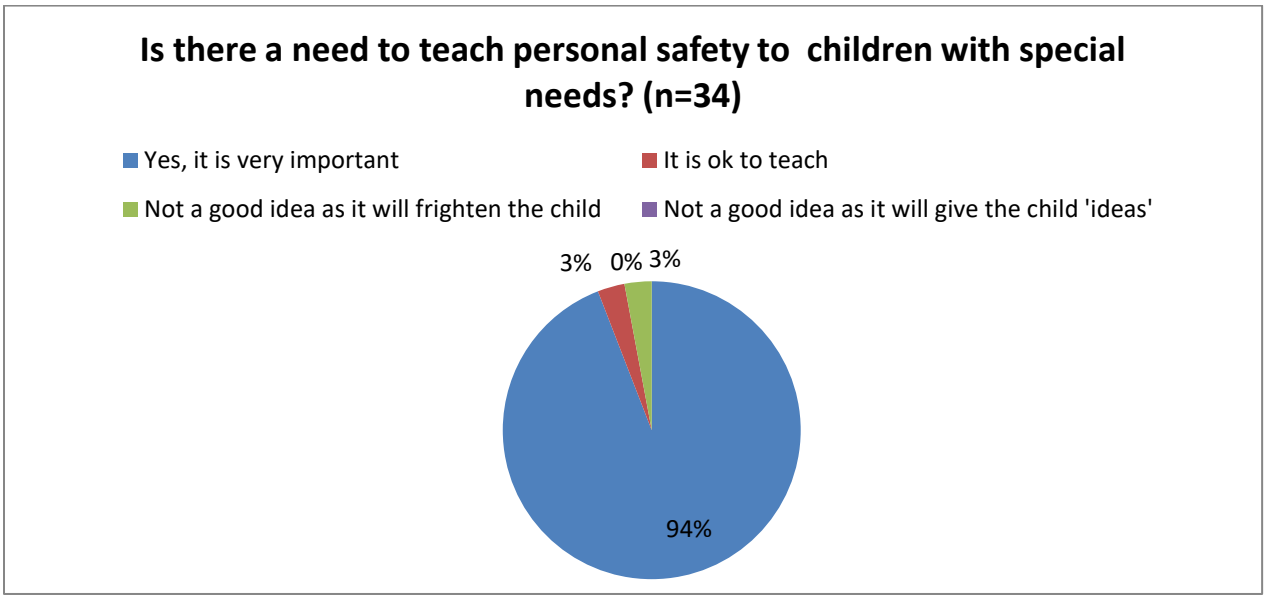
At the beginning of the Suvidha project, a need analysis was carried out to identify the beliefs and concerns of the caregivers that need attention while developing the kit, thereby making it relevant for the end users. The results and discussion of some of the findings from the need analysis are presented below:

i. Challenges while teaching children personal hygiene



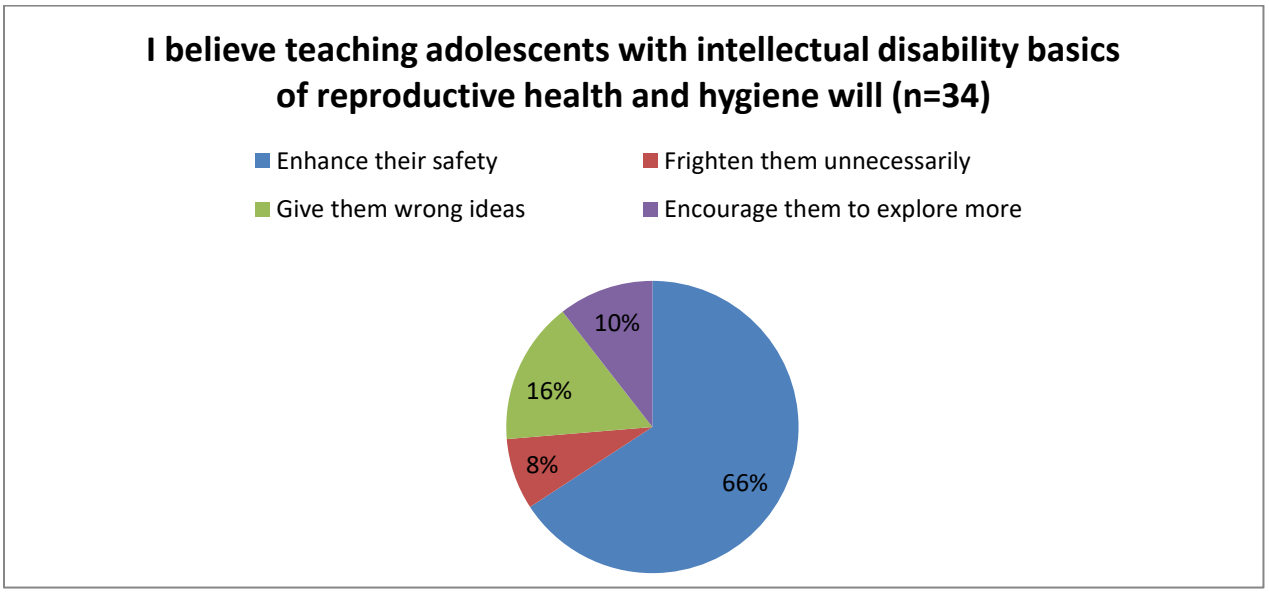
50% of respondents said that they have insufficient tools and methods to teach personal hygiene to children with ID. 23% of respondents said that they find it challenging to sustain attention of children. The remaining respondents expressed that they do not know the right signs or language (15%) and some of them know the words, but do not feel comfortable talking about this (12%).

ii. Need to teach personal safety to children with special needs



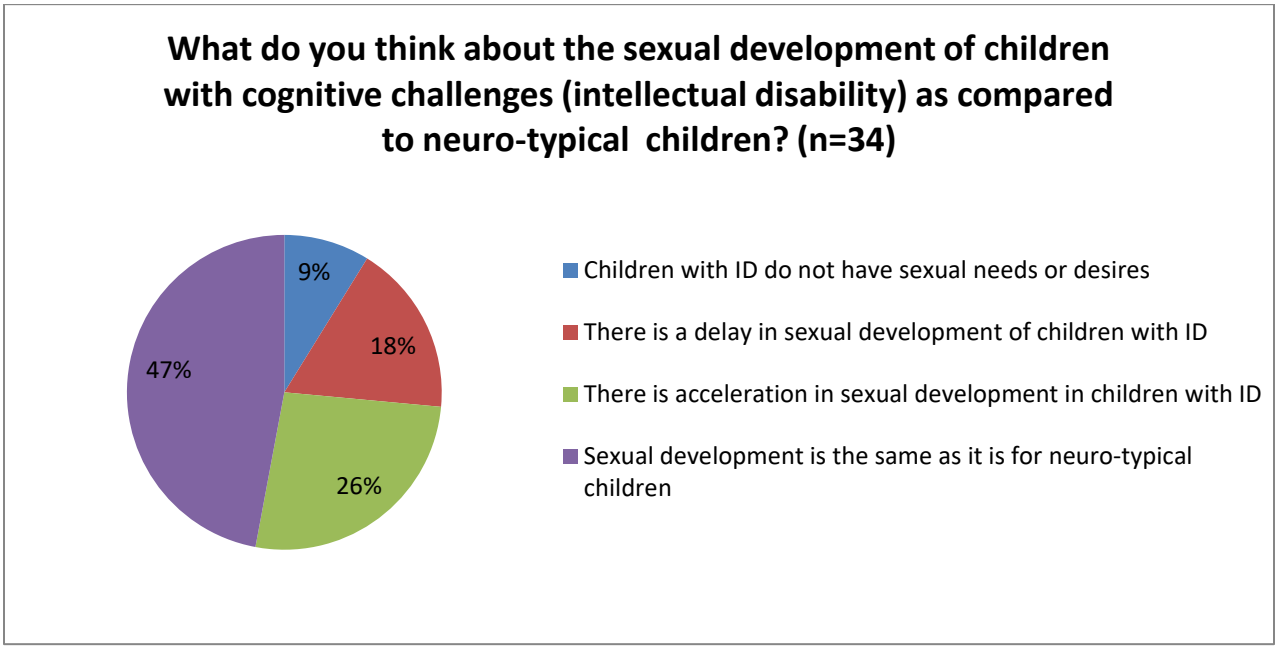
94% of the respondents said that it is very important to teach personal safety to children with special needs. None of them said that it is not a good idea as it will give the child 'ideas'. However a small number of respondents (3% each) believed that teaching personal safety to children will frighten the children and it is somewhat ok to teach them the same.

iii. Effect of teaching basics of reproductive health and hygiene



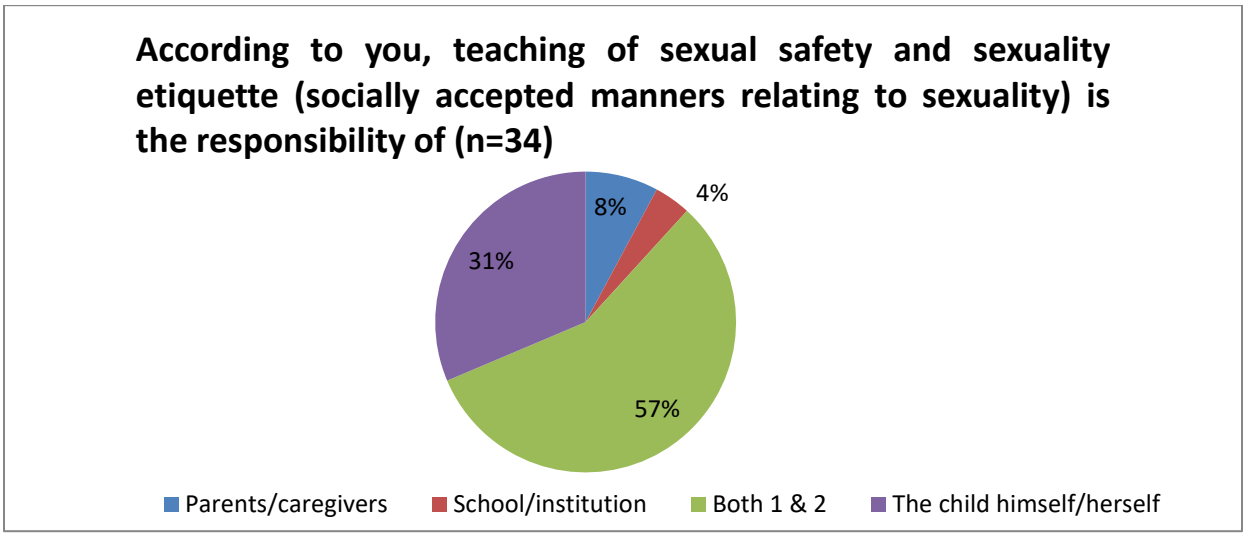
66% of respondents said that they believe teaching basics of reproductive health and hygiene will enhance the safety of children with ID. The remaining number of respondents believed that this will give them wrong ideas (16%), frighten them unnecessarily (8%) and encourage them to explore more (10%).

iv. Sexual development of children with ID



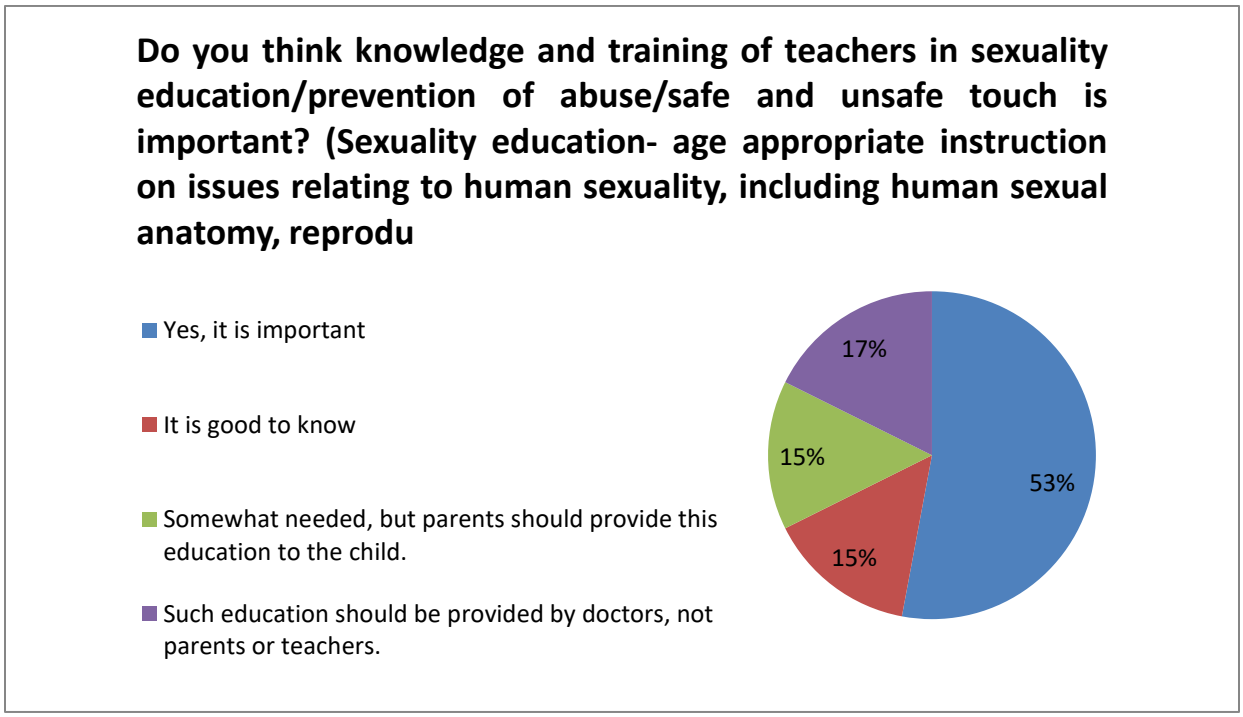
47% of respondents agreed that sexual development in children with ID is same as it is for neuro-typical children. 26% of respondents believe that sexual development is accelerated in children with ID whereas 18% of them believe that it is delayed. However it was also found that some respondents (9%) believe that children with ID do not have sexual needs or desires.

v. Teaching sexual safety and sexuality etiquette



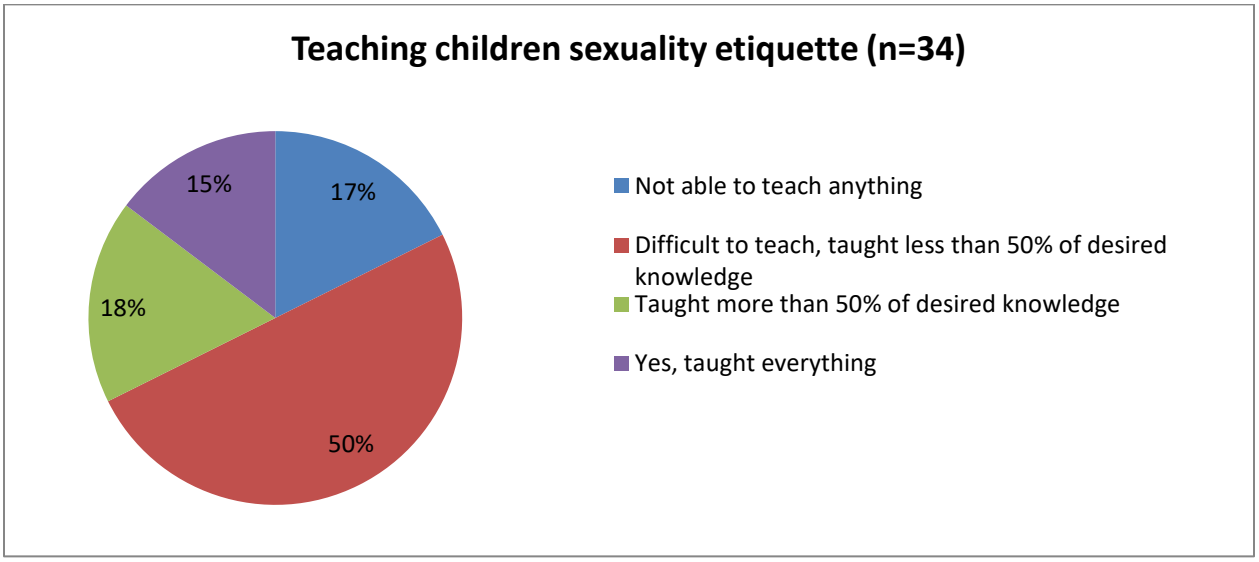
57% of respondents said that it is the responsibility of both parents/caregivers and school/institution to teach sexual safety and sexuality etiquette. However a considerable number of respondents (31%) said that the child himself/herself holds the responsibility to learn sexual safety and sexuality etiquette.

vi. Importance of knowledge and training teachers in sexuality education/prevention of abuse/safe and unsafe touch



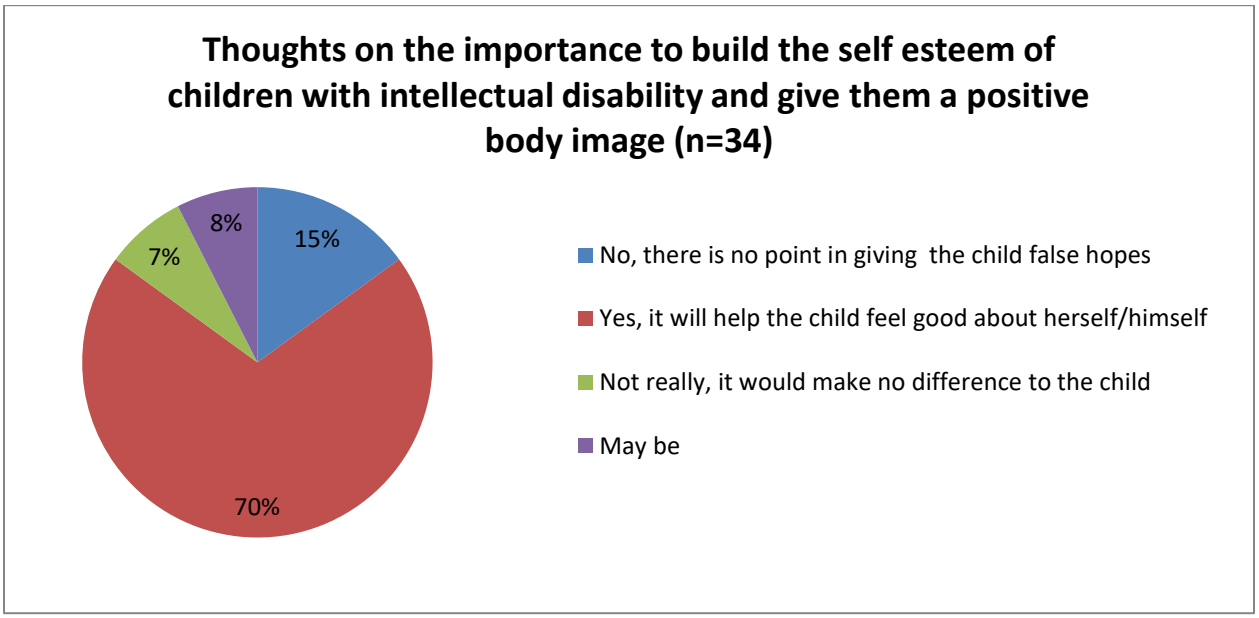
53% of respondents said that it is important for teachers to obtain knowledge and training in sexuality education, prevention of abuse and safe/unsafe touch. However 17% of respondents said that such education should be provided by doctors, not parents or teachers. Remaining respondents believed that it is good to know about it (15%) and that such education is somewhat needed, but parents should provide this education to the child (15%).

vii. Teaching children sexuality etiquette



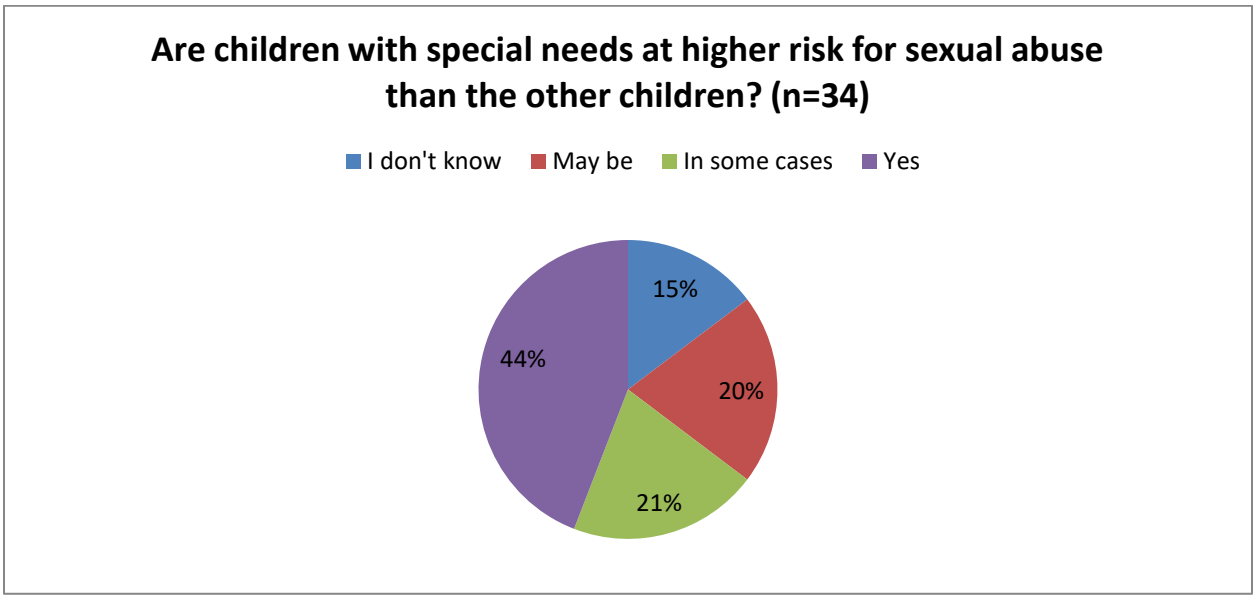
50% of respondents said that they find it difficult to teach sexuality etiquette. A considerable number of respondents (18%) said that they are able to teach more than 50% of desired knowledge and 15% of them said that they are able to teach everything. There were also respondents (17%) who said that they are not able to teach anything related to sexuality etiquette.

viii. Importance of building self-esteem and positive body image in children with ID



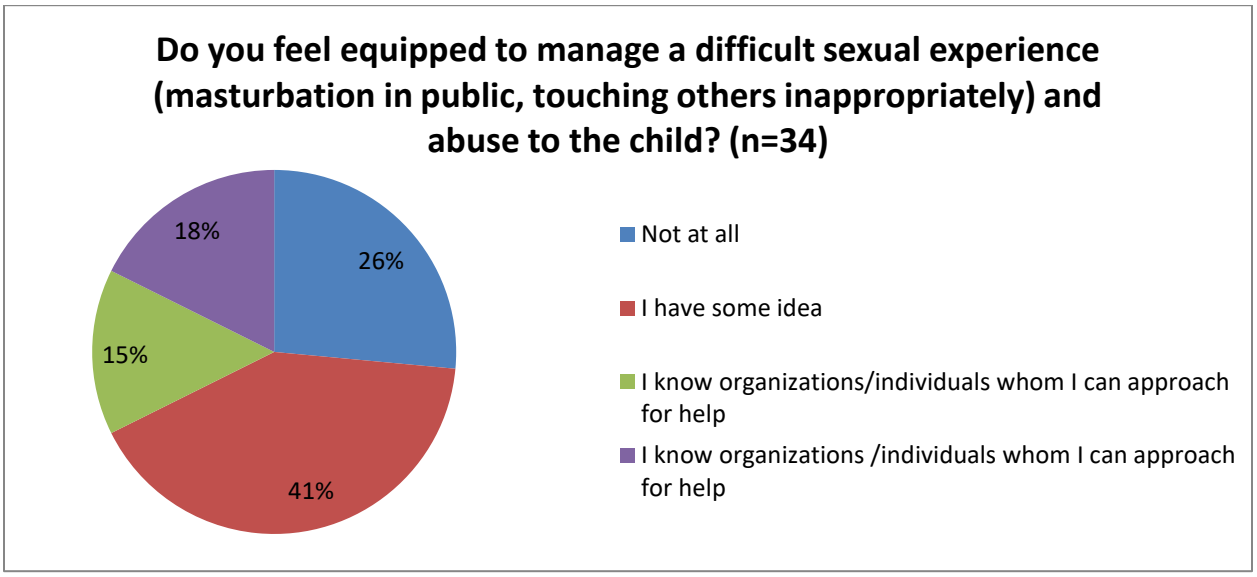
70% of respondents said that building self-esteem and positive body image among children with ID will help children feel good about her/himself. However a considerable number of respondents (15%) said that there is no point in giving children false hopes about building self-esteem and positive body image.

ix. Risk of sexual abuse among children with special needs



44% of respondents said that children with special needs are at higher risk for sexual abuse than other children. Some respondents said that it may happen in some cases only (21%).

x. Managing a difficult sexual experience and abuse



41% of respondents said that they have some idea about managing a difficult sexual experience and abuse among children with special needs. A considerable number of respondents (26%) said that they do not feel equipped in any manner to manage difficult sexual experiences and abuse among children with special needs.

V. Conclusion from the need analysis:

The findings of the need analysis revealed the following significant results which further support project goals and proposed modules stated in the next section:

- Majority of respondents (50%) said that they have insufficient tools and methods to teach personal hygiene to children with ID
- Majority of respondents (94%) said that it is very important to teach personal safety to children with special needs
- Majority of respondents (66%) said that they believe teaching basics of reproductive health and hygiene will enhance the safety of children with ID
- Majority of respondents (47%) agreed that sexual development in children with ID is same as it is for neuro-typical children
- Majority of respondents (57%) said that it is the responsibility of both parents/caregivers and school/institution to teach sexual safety and sexuality etiquette
- Majority of respondents (53%) said that it is important for teachers to obtain knowledge and training in sexuality education, prevention of abuse and safe/unsafe touch
- Majority of respondents (50%) said that they find it difficult to teach sexuality etiquette
- Majority of respondents (70%) said that building self-esteem and positive body image among children with ID will help children feel good about themselves
- Majority of respondents (44%) said that children with special needs are at higher risk for sexual abuse than other children
- Majority of respondents (41%) said that they have some idea about managing a difficult sexual experience and abuse among children with special needs. A considerable number of respondents (26%) said that they do not feel equipped in any manner to manage difficult sexual experiences and abuse among children with special needs

VI. The Need for Suvidha Kit

A significantly positive relationship was found between the age of the child and the parental need for information on sexuality, marriage, vocation, and future plan by Rajesh Verma and M Thomas Kishore[7]. Identifying and supporting the parents in their efforts to meet the needs is one of the most efficient interventions to develop parental skills, which can facilitate the development of all family members (Peshawaria et al., 1995).

In India, education in personal safety and sexuality is not a norm. A review of school text books and our interactions with thousands of children and parents has made it clear that neuro-typical children do not receive this education adequately either at home or at school. Our teachers and parents do not know how to impart this education as it is not a part of the B.Ed or other courses. Indian teachers and parents therefore are not well equipped to impart this education to children with cognitive special needs.

There is especially a dearth of indigenously developed culturally appropriate educational material on sexuality and safety education for these children. Teaching-learning kits dedicated to this purpose have not been developed in India, neither are they readily available in India.

Over the last 15 years Enfold has developed culture and age appropriate value based curriculum on life skills, personal safety and sexuality. To develop this kit, existing material was researched and methodologies used to help children with ID learn concepts and skills were identified. Simple basic concepts from our existing curriculum have been used to develop 2 prototypes. Once the prototypes are tested through caregivers, teachers and children, and finalised, similar modules will be developed on self-esteem and body image. After testing and modification, the final kit will be made available in the public domain.

Suvidha Learning modules - For 6 to 11 years old children with cognitive special needs

Module 1 – My abilities and behaviour	Module 2 – Body image and behaviour	Module 3 – My Feelings	Module 4 – My Body and Body Safety Rules	Module 5 – Stopping the Rule Breaker
I have qualities and abilities	My body is made by nature	I have many different feelings	I know the parts of my body	I say No – Go away – Tell my Safe Adult if rules are broken
I can help my brain and body develop – foods, activities, avoiding TV	My behaviour is more important than how my body look	Expressing feelings helps me feel better and get help	I keep my body clean	I can report unsafe behaviour to my Safe Adult
Girls and boys can do many different activities	The way a person behaves tells me about that person.	It is okay to discuss embarrassing feelings with people who care for me. (passing urine in a bus)	Rules are for my safety	I can tell until I get help
			We often touch each other while talking/ playing	
			Body Safety Rules about clothing, touching and talking in front of others	
			I follow Body Safety Rules - which body parts can be uncovered/ touched/ talked about casually	

Suvidha Learning modules - For 12 to 18 years old children with cognitive special needs

Module 1 – My Self	Module 2 – My Body	Module 3 – My Feelings and My Behaviour	Module 4 – My Body and Body Safety Rules	Module 5 – Asking for help
I have qualities and abilities	I am experiencing new changes in my body	My behaviour is more important than how my body looks	Rules are for my safety	People's behavior (including how they touch me) may be safe or unsafe
I can help my brain and body develop – foods, activities, avoiding TV	I know the parts of my body	I can express feelings in a way that helps	We often touch each other while talking/ playing	When someone breaks a safety rule: NO. GO. TELL
Girls and boys can do many different activities	Every part has a function	I can express anger without hitting/hurting others	Body Safety Rules about clothing, touching and talking in front of others	It is not my fault if someone troubles me. The trouble maker is to be blamed.
I neither take pride in nor feel ashamed of my body	I keep my body clean	The behavior of a person tell us about the character of that person	I follow Body Safety Rules - which body part can be uncovered/ touched/ talked about casually	I can report unsafe behaviour to my Safe Adult
		I can make friends with people who care for me and keep me safe	I can be safe while using the phone/ camera/ internet	I can go on telling until someone listens and stops the abuser

Sudhiva Project Goals:

1. To develop culturally appropriate teaching and learning modules and kit on Personal Safety, basics of reproductive health and Sexuality Etiquette for caregivers of children with cognitive special needs
2. To empower caregivers, teachers and parents of children with intellectual disability to feel comfortable with the topic of sex and sexuality. The caregiver/parent understands and is comfortable with sexual development of children and adolescents. The caregiver/parent is comfortable with her/his own sexuality.
3. To break the silence around reporting of sexual abuse and bring about a cultural shift by shifting the shame, blame and responsibility of child sexual abuse and sexual assault from the target of abuse to the perpetrator. Help the caregivers/parents recognize, resist and report sexual abuse in an empowering manner
4. To provide caregivers, teachers and parents of children with intellectual disability with the tools, concepts and principles that will

a) help children build their self- esteem
b) help children develop a positive body image
c) help children learn Personal Body Safety Rules and how to report if these rules are broken by someone
d) help adolescents with intellectual disability learn basics of reproductive health and sexuality etiquettes

5. To train 20 teachers/parents as Personal Safety and Sexuality Educators for children with ID

Expected outcome:

A) A complete teaching learning kit with

1. Preparatory reading material for caregivers of children with cognitive special needs to help them understand the development of sexuality in children, basic information on reproductive health, awareness of child sexual abuse and how to recognize, resist and report perpetrators of sexual abuse, POCSO Act 2012 and their socio-legal responsibilities.
2. Facilitation manual for caregivers complete with activities, role plays that they can use to teach the two age groups of children.
3. Supportive material like games/ puppets/ puzzles/ charts/ picture book and other appropriate material that can be used by the caregiver to help the children with cognitive special needs learn the concepts.

B) 20 Personal Safety and Sexuality Educators for Children with Intellectual Disability. These educators will be well versed in using the Suvidha Kit

VII. Conclusion and way forward

According to UN Enable, around 10% of the world's populations, 650 million people, live with disabilities. Women and girls with disabilities are particularly at a risk of abuse.

In India 1.67% of the 0-19 population has a disability. Census 2001 has revealed that over 21 million people, equivalent to 2.1% of the population in India suffers from one or the other kind of disability. Among the five types of disabilities (seeing, movement, mental, speech and hearing) mental disability was recorded in 10.3% of the 21million people living with disability

By learning to impart this education to the children with ID, the teachers, parents and care givers will learn how to teach *any* child personal safety and responsible sexuality. They will be able to talk to other children in their family/ care. This will be an added benefit.

The 20 Personal Safety and Sexuality Educators for Children with Intellectual Disability will be able to train or guide other staff in their institution or elsewhere, as well as support parents in using the Suvidha Kit. Current training of teachers of children with special needs in India does not prepare them for this task. These educators could also spread the word about the kit to institutions in different cities and towns in India.

Sustainability plan

The kit, once developed, tested and used will be accessible to educators/caregivers of children with cognitive special needs across India. The cost of making this kit in bulk will be affordable. Since this kit is being developed by Enfold Proactive Health Trust using its already existing Intellectual Property (Enfold Modules on Life Skills, Sexuality and Personal Safety Education) the kit will be made and sold an affordable price to potential users. Alternatively the Kit could be mass manufactured by a philanthropic organization and distributed free of cost to the caregivers.

20 Personal Safety and Sexuality Educators for Children with Intellectual Disability will be able to train or guide other staff in their institution or elsewhere, as well as support parents in using the Suvidha Kit.

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