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**Personal Safety, Sexuality Etiquette and Reproductive Care Education for Children with
Intellectual Disability, Auditory and Visual Impairments.**

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Abstract

The status of children in India is often that of objects of protection rather than citizens with equal rights. Children especially those with disabilities, are often denied their right to education on personal safety, sexuality and reproductive health, in spite of them being at a greater risk of all forms of abuse and sexual violence. Social taboos, lack of teaching skills and paucity of culturally appropriate teaching materials on these subjects, makes it even more difficult for caregivers and trainers of these children to help them learn these life skills of critical importance.

Having worked since 2002 with over 1,60,000 neuro-normative children and adults on sexuality and personal safety education, Enfold Trust felt equipped to venture into the space of providing education on personal safety education for neuro-atypical children and those with visual and auditory impairments through the Suvidha project.

Objectives:

1. Develop a Toolkit – “Suvidha”- for caregivers/teachers of children with ID, AI and VI to
 - (a) Develop comfort with the topic of sexuality
 - (b) Understand sexual development in children
 - (c) Support children/adolescents develop self-esteem, manage their feelings, learn personal safety and basics of reproductive health and sexuality etiquette
2. To train facilitators across India as Personal Safety and Sexuality Etiquette Educators for children with intellectual disabilities, visual or auditory impairments

Method:

Theories of cognition, metacognition, structured teaching and PECS were used to create the ‘Suvidha’ toolkit. Core messages were drawn from Enfold’s existing sexuality and safety curriculum for mainstream schools.

Steps:

- (1) Need analysis
- (2) Research existing material
- (3) Interactions with caregivers and teachers
- (4) Develop tool kit “ Suvidha” with inputs from experts
- (5) Field testing in Special Needs and Inclusive Schools; parents.
- (6) Incorporate test results; retest if required.
- (7) Release the final kit

Results: Need analysis was done among 158 adults. Only 34% of teachers and 23% of parents surveyed talked about safe/unsafe touch with the children. Testing of activities: 43 parents reported that ‘children learning to keep private parts covered in public at all times’ increased from 32% to 53.5%. Among 32 teachers ‘ease with naming private parts’ increased from 53% to 92%.

Reach : So far , we have reached more than 600 parents and teachers, across 5 states and 21 schools, through direct face to face interactions and workshops, on using the Suvidha Kit and how to talk to children with disabilities about personal safety, sexuality etiquette and reproductive care

Way forward:

The kit is being given final touches by professional artists and is being adapted for children living with auditory and visual impairment through audio books, tactile and embossed diagrams and sign language videos. Manufacturing of the kits will be done at vocational centres training and employing people with disabilities across India. The kit will be translated into Hindi, Kannada and later into other languages

Conclusion

Children with disabilities have been living their lives under the radar for far too long, struggling to realise their rights and agency. Enfold plans to reach children, parents, caregivers and teachers all over India to ensure that they have an equal platform for safety and dignity.

Full Paper

Rationale

Accounting for 12 lakhs of India's population, the silence around the sexual, physical and emotional abuse of children with disabilities is astounding. Children with disabilities are systematically denied basic information about sexual health and relationships, to either shield them from the realities of life or because they are considered asexual. Without such fundamental lessons, children with disabilities have no language to describe what has happened to them when they are abused. (Smith, N., Harrell, S. et. al (2013)⁴

The status of children in India remains as objects of protection rather than citizens with equal rights. While adults are educated about their rights and responsibilities, children are often left out of the fold, especially in matters of personal safety, sexuality and reproductive health. The lacunae in information prevents children from being able to recognise, resist and report abuse, whether emotional, physical or sexual. This inherent disadvantage is exemplified by the dismal statistics on crime against children.

In a 2007 study on Child Abuse in India conducted by the Department of Women and Child Development, among 12447 children (without disability) in 13 states,

- 53.22% children reported having faced one or more forms of sexual abuse.
- 21.90% child respondents reported facing severe forms of sexual abuse.
- in 50% of those reporting abuse, the persons were known to the child.

A study by Tharinger, Horton and Millea² (1990) found that children and adults with intellectual disabilities are particularly vulnerable to sexual abuse. Sullivan and Knutson³ (2000) found that children with intellectual disabilities are 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 and at 2.9 times greater risk of sexual violence than non-disabled children



People with disabilities are often assumed to be either ‘asexual’ or ‘oversexed’. Society largely considers them unattractive and therefore incapable of being in sexual or in intimate relationships, leading to the belief that people with disabilities do not get sexually assaulted or abused as no one will desire them.(Kaufman, M, Silverberg, C and Odette 2003)⁵.

However, the fact is that children and adults with disability experience these bodily changes and feelings just as their neurotypical counterparts and may express them in socially inappropriate ways, as their rights to dignity and education have not been addressed. Recognising that they are equal humans, citizens and participants and not just passive recipients of resources or information, is as vital to their empowerment, as it is to preventing abuse and maltreatment.

(I) The Need for Education in Personal Safety and Sexuality Etiquette

Indian society, parents and teachers either shy away from discussing sexuality and personal safety with children or do not think it as necessary. There is a real lack of awareness about the possibility or extent of sexual abuse due to the silence and stigma around sexuality. Such ignorance and indifference makes children more vulnerable to sexual abuse.

Disabilities, especially intellectual disability, increases the likelihood of sexual abuse due to several factors including the unique features of the disability itself.

Enfold Proactive Health Trust has worked with over 1.6 lakh regular school going children from 1st to 12th grade since 2001 in the field of personal safety, sexuality and life skills education. Equipped with adequate experience and expertise, we took up the challenge to address the need for facilitating neuro- atypical children learn personal safety and sexuality etiquette in non inclusive as well as inclusive settings. Developing a teaching learning ‘Suvidha’ kit was taken up as a way forward in this field.

In November 2016, we began the Suvidha Project, to develop a one of its kind, interactive, easy to use teaching learning tool, the Suvidha Kit.

(II) Goals and Objectives:

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 intellectual disabilities, visual and auditory impairments

1. To break the silence around discussion on sexuality and reporting of sexual abuse. Bring about a cultural shift by placing blame and responsibility of sexual abuse and sexual violence from the victim to the perpetrator.
2. To empower caregiver, teachers and parents of children with IDD, AI and VI to recognize, resist and report sexual abuse.
3. To provide materials, tools, concepts and principles to caregivers, teachers and parents , that will enable them to support children and adolescents to-
 - a. build their self- esteem
 - b. develop a positive body image.
 - c. learn personal safety rules in a comfortable, non threatening manner
 - d. learn how to report if personal safety rules are broken by someone.
 - e. Learn basics of reproductive health and sexuality etiquettes.
4. To train facilitators in 36 states and union territories as Personal Safety and Sexuality Etiquette Educators for children with IDD, AI and VI

(III) Methodology

The Activities that were undertaken to develop the Suvidha Kit are:

1. Research existing material being used
2. **Need Analysis:** Interact with parents, caregivers and teachers of children with IDD, AI & VI to understand the materials currently in use and their difficulties vis a vis teaching personal safety and sexuality related concepts.
3. Develop content of the Suvidha Kit. Opinion of Experts working in this area was sought and incorporated.

4. The prototypes for various activities have been tested through caregivers and teachers at our collaborating schools in Bangalore and other cities across India and in Kuwait.
5. Feedbacks from the field test analysis has been incorporated. Manufacturing of the kit and its release in the market is being aimed by March 2019.

Need Analysis: Identifying challenges

Study sample: 158 adults comprising of 65 teachers/trainers and 93 parents/caregivers working with children with IDD in Bangalore and Raipur.

Procedure: The assessment tool was created by Enfold Experts and was administered either directly or as a Google form in English, Kannada and Hindi in Bengaluru and Raipur.

Results and Discussion:

Key findings:

- 52% of teachers and 56% of parents said that they find it difficult to teach sexuality etiquette, 14% of teachers and 30% of parents admitted not being able to teach anything.
- 34% of teachers and 46% of parents said that they have do not feel equipped in any manner to manage difficult sexual experiences and abuse of children with IDD.
- Only 34% of teachers and 23% of parents are able to talk about safe unsafe touch with the children.

Based on the challenges identified, the following topics have been included in the Suvidha Kit:

Contents of the Suvidha Kit:

Suvidha Kit is for use with children between the age group of 6-18yrs, with activities designed to cater to the needs of children at different functioning levels as well.

The Kit contains

1. A Caregivers Manual with
 - a. Concepts and information pertaining to the activities to be done with children.
 - b. Further reading material and references

2. A Tool Kit with
 - a. Teaching-learning materials for use with children and adolescents,
 - b. Activity guide for each set of activities.

The concepts and activities cover the following topics:

Module 1 My Abilities and Behaviour

Module 2 Body Image and Behaviour

Module 3 My Feelings

Module 4 My Body and Personal Safety Rules.

Module 5 Getting Help, Stopping the Rule Breaker

(IV) Results and Discussion

a.Pre and post- test on learning names of private parts and Personal Safety Rule on Clothing

Procedure:

This activity was introduced to 40 parents and 40 teachers through interactive sessions at 4 schools in Bangalore between April and November 2017.

Study sample:

Pre test -69 adults in Bangalore - 37 parents and 32 teachers

Post Test (after 3 months of teaching) -61 adults -34 parents and 27 teachers.

Few highlights:

- Before the activity, only 29.7% of parents said their child had learnt to keep the private parts covered in public at all times. This increased to 53.5% of parents after the activity.
- Before the activity only 9% of the teachers said that 51-75% of their students kept the private parts covered in public, this increased to 37% after the activity

- On the 'importance of the child knowing the names of the private parts percentage of teachers agreeing increased from 75% to 92.6%.
- About being comfortable teaching names of private parts, the responses of teachers increased from 53% to 74.1% after the activity, a marked increase in the confidence and comfort levels.
- Parental behavioural change regarding being clothed appropriately in front of the child- increased from 70.3 % to 86%.

b. Parent's pre test on Personal Safety Rules - Touching Rules

Field testing of this was initiated in December 2017, with 37 parents with children in the age group of 10-17 years. Only 9 parents responded in the post test data collection. Rest are awaited.

Key findings:

1. Children touching their private parts in public frequently reduced from 8.1 % to 0%, those touching occasionally reduced from 32.4 to 22.2 %
2. Children touching others' private parts reduced from 2.7 to 0 %

c. Parent's pretest: Changes in my body and Reproductive care

1. Asked if the child touches private parts/ masturbates intentionally in public, 36.4% parents said that their children masturbate both in private and public
2. On the frequently of child touching private parts/ masturbating intentionally in public, 36.4 % said their child did it occasionally
3. Asked if there is an open communication between parent and their child regarding sexuality and its management, 10% parents said they found it difficult and 70% said they communicate only sometimes..

Post test results are awaited.

(V) Dissemination Plan

Enfold proposes to undertake the following activities to scale the product effectively:

➤ **Illustration of the complete kit**

The preliminary field testing kit is being illustrated by Bangalore based artists, and will be ready for manufacturing in March 2019.

The Kit for use by children with VI will have suitable embossed images and text in Braille, along with audio files. The material to be used by children with AI will have videos with sign language.

➤ **Adaptation of the Kit to suit linguistic abilities**

In 2019, the Kit will be made available in Kannada and Hindi initially. The long term goal however, is for the Kit to be made available in as many regional languages as possible for ease of access.

➤ **Production**

In order to empower not just children with disabilities, but also adults with disabilities in need of employment opportunities, Enfold intends to partner with an organisation providing such opportunities to individuals with disabilities, in each state. They would translate and/or produce the kit.

➤ **Training facilitators of the Suvidha Kit across the 29 states and 7 union territories**

The population of children with disability is spread all across the country, with 69% concentrated in rural areas. While Enfold has worked extensively with urban education children in metro

cities, we would like to extend our network to reach out to children living in all rural, semi rural areas.

In a phased manner, Enfold will be providing training and capacity building sessions for 2 members in every partner organisation in 29 states and 7 union territories.

Each Educator will be trained for a minimum of 100 hours in a stepwise manner. Certificate will be given at the end of successful completion of 100 hours of training.

Step 1. Face to face or online training:

Step 2. Self- study and assessment on subject:

Step 3. Use the kit for 50 hours with children with IDD, AI and VI

(VI) Conclusion

The results of pre-test and post- test on the activities tested are encouraging. They show a positive change in knowledge of children and attitude and behaviour of parents and teachers.

From anecdotal accounts from teachers and parents, it appears that Personal Safety and Sexuality Etiquettes can be taught in an inclusive school or home setting. Parents can reinforce the learning at home for neuro-atypical as well as neuro-typical children.

Children with disabilities have been living their lives under the radar for far too long, struggling to realise their rights and agency. Enfold plans to reach children, parents, caregivers and teachers all over India to ensure that they have an equal platform for safety and dignity.

(VII) Bibliography

1. Study on Child Abuse India 2007 by Govt of India, Min of Women and Child Development, UNICEF and Prayas, 2007
2. Tharinger D, Horton CB, Millea S. (1990). Sexual abuse and exploitation of children and adults with mental retardation and other handicaps. *Journal of Child Abuse and Neglect*. 14(3), 301-312
3. Sullivan, Patricia and M, Knutson, John F. (October 2000). Maltreatment and disabilities: a population-based epidemiological study. *Journal of Child Abuse and Neglect*. 24(10), 1257-1273
4. Smith, N., Harrell, S. et. al (2013) Sexual Abuse of Children with Disabilities: A National Snapshot. US: Vera Institute of Justice: Centre on Victimization and Safety. [Online]
5. KAUFMAN, M, SILVERBERG, C and ODETTE, F (Eds). 2003. The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain and Illness. (Powell's Books. San Francisco)
6. TARSHI. (2010). Sexuality and Disability in the Indian Context – working paper