

## Background

In our day-to-day lives, we meet many people, some of whom have specific conditions. According to the Census (Ministry of Statistics and Programme Implementation, 2011), 2.68% of India's total population lives with some form of disability. According to a report, an estimated 0.04% (more than 500,000) of India's total population lives with Deafblindness. A recent report by the World Federation of Deafblind indicates that 0.2% to 2% of the world's population lives with Deafblindness (World Federation of Deafblind, 2018). Deafblindness has now been included in the Rights of Persons with Disabilities Act, 2016. Under this Act, special rights have been provided for Individuals with Deafblindness, including accessible education, employment reservations, and more.

Deafblindness is a combination of varying levels of vision and hearing loss in a person. It is a unique disability that brings significant challenges for an individual. There are many causes of Deafblindness. It affects people of all ages in different ways, and no two Individuals with Deafblindness are the same. Approximately 95% of what we learn about our environment comes through vision and hearing. Individuals with Deafblindness do not have this opportunity and must learn and understand everything using their remaining sensory abilities, which contribute only about 5%. Individuals with Deafblindness face immense challenges in communication, mobility, and learning various skills, which isolates them from the world around them. They have specific educational, vocational training, and other needs. However, due to a lack of adequate services and resources, Individuals with Deafblindness often experience isolation, both within their own homes and at a broader social level.

India's largest population resides in rural areas, where most Individuals with Deafblindness cannot access their rights due to a lack of appropriate services and opportunities. It is evident that very few institutions provide necessary education, training, and rehabilitation services to Individuals with Deafblindness due to reasons related to skills, expertise, and financial resources. There is a lack of awareness about Deafblindness among the general public, policymakers, medical and paramedical professionals, development planners, and non-governmental organizations.

Understanding the needs of Individuals with Deafblindness and providing personalized services is a challenging task. Additional disabilities or developmental delays further increase complexities and individual requirements. Many times, special educators and community workers face difficulties in carrying out community-based rehabilitation for Individuals with Deafblindness. Keeping this in mind, this book has been designed to help understand the nature of Individuals with Deafblindness and their community-based rehabilitation programs, ultimately assisting in their full inclusion in society.

## Acknowledgement

First and foremost, we would like to extend our heartfelt gratitude to all Children with Deafblindness and adults, their family members, partner organizations, and special educators who have given us the opportunity to understand the unique world of Individuals with Deafblindness. Without their support, we would not have been able to gain this experience, upon which this booklet on education and rehabilitation is based.

We would also like to thank the dedicated team of the Deafblind Regional Centre (DbRC) - East for their relentless efforts in providing quality and continuous services to Children with Deafblindness and adults in the eastern region of India. The contribution of this booklet goes to them, along with the support of the Sense International India Resource and Information Team members.

We are also grateful to the Paul Hamlyn Foundation and other collaborators for their financial support in developing this resource material, which plays a crucial role in raising awareness about Deafblindness in society.

**Disclaimer:** Every possible effort has been made to ensure the accuracy and authenticity of the information presented in this book. All images included in this book have been used with the consent of the families of Individuals with Deafblindness. This book should be used solely as a general guide and not as the final authority on writing and publishing information. Its primary purpose is to educate readers and should not be interpreted as a reflection of the views of Akanksha Lions Institute of Learning and Empowerment, Sense International India, or the Paul Hamlyn Foundation in any way.

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## Introduction to Deafblindness



## Concept of Community Based Rehabilitation



## Key Members of Community Based Rehabilitation

### Community Members

- Parents
- Family Members
- Neighbours
- Gram Panchayat
- Public Representatives
- Other Social Workers



### Social Organizations

- Special Schools
- Program Officers
- Community Workers
- Various Paramedical Professionals (Therapists)
- Vocational Trainers

### Community Members

- Community Health Centre
- Anganwadi Worker
- ASHA Worker
- Inclusive Schools
- District Hospital
- District Rehabilitation Centre
- Government Vocational Training Centre, etc.

## **Strategies for Community Inclusion of Children with Deafblindness**

**Understanding the Community Environment**

**Identifying Available Resources in the Community**

**Coordination and Communication with Community Representatives**

**Engagement with District and Primary Health Centre Staff**

**Liaising and Coordinating with Anganwadi Centres for Children with Deafblindness**

**Raising Awareness Among Families and the Community About Deafblindness**

**Guiding Parents on their Child's Education and Rehabilitation Opportunities**

**Medical Examination of Children/Adults with Deafblindness**

**Assessment of Functional Abilities of Children/Adults with Deafblindness**

**Guiding Parents on Their Child's Education and Assessing the Functional Abilities of Children/Adults with Deafblindness**

## Strategies for Community Inclusion of Children with Deafblindness

### Role of Community Workers and Coordinators

Identifying Deafblind Individuals in the Community

Finding Available Resources in the Community

Raising Awareness Through Posters, Street Plays, etc.

Providing Information About the Work Done by Your Organization

Educating Parents About Their Child's Condition

Assisting in Obtaining a Deafblindness Certificate

Helping in Accessing Educational Materials, Assistive Devices, and Facilities

Informing Panchayat Members About the Needs of Individuals with Deafblindness

Raising Awareness in Inclusive Schools

Supporting Children with Deafblindness in Receiving Special Education

Providing Information About Anganwadi Services, Inclusive Education, and Self-Employment

Offering Pre-Vocational Training

Guiding Parents on Healthcare Centers

Informing Parents About District Rehabilitation Centers



## Role of Family and Community in the Education of Deafblind Children



### Role of the Family

- Implementing the guidance provided by teachers
- Helping the child learn essential skills
- Providing emotional support to the child/adult
- Paying attention to the child's health
- Contributing to skill development for the child/adult
- Maintaining a positive outlook toward the child's growth

### Role of the Community

- Providing emotional support to families
- Including deafblind children/adults in community programs
- Maintaining records of deafblind individuals at the village level
- Encouraging play and interaction with other children in the community
- Prioritizing employment opportunities and facilities for deafblind individuals



## Role of Family and Community in the Education of Deafblind Children



I am Anjali Chauhan, a resident of a small village in Abhanpur, Raipur. My world was once limited to the reach of my fingers. Whatever my hands could touch was my entire universe.

During my childhood, my parents worked as daily wage labourers. After sending my siblings to school, they would leave for work, and I would remain alone in a locked room. I struggled to understand my surroundings, and my family members felt helpless because they could not communicate with me. This created a gap between us, leaving me isolated.

However, one day, my life changed when an uncle from Akanksha School visited our home. He worked with children like me, teaching them essential life skills. His visit brought a ray of hope into my parents' lives. He started teaching me small yet important skills that could help me live a better life. It took my parents six months to learn how to communicate with me.

Later, Sense International India organized a parents training program in Ahmedabad. My mother participated in this program and realized that there were many children like me who were learning effectively and showing significant improvement in their behaviours. Inspired by this, she decided to teach me everything she had learned.

With the help of my special educator, my mother began teaching me household tasks such as washing clothes, eating, bathing, going outside, washing utensils, cutting vegetables, engaging in social interactions, and communicating with others. Gradually, I was included in every community event, where I participated in games with other children, went to the pond for a bath, and took part in social activities without any difficulty.

My special educator also taught me how to make Garlands, making Rakhi, and handle money transactions. Over time, I mastered these skills. To help me become financially independent, Sense International India provided financial support to open a fancy store. Today, with the help of my sisters, I sell fancy items. Instead of being a burden on my parents, I now contribute to running the household, and this brings me immense happiness.

## Role of Family and Community in the Education of children with Deafblindness

Akanksha Lions Institute of Learning and Empowerment, with the support of Sense International India, has established the Deafblind Regional Centre (DbRC-East) for the eastern region. This centre serves Bihar, Jharkhand, West Bengal, Odisha, and Chhattisgarh. We provide direct services to Children and individuals with Deafblindness and while also delivering services through partner organizations. Our mission is to build the capacity of partner organizations and NGOs working in the field of Deafblindness, enabling them to reach Children and individuals with Deafblindness and offer them the necessary educational and pre-vocational services.

DbRC is committed to implementing high-quality services for Children and adults with Deafblindness. Additionally, it plays a key role in raising awareness and providing training on Deafblindness and multiple sensory impairments to professionals, including special educators, community workers, therapists, paramedical professionals, government officials, and inclusive education teachers.

### Centre Based Education



This is a structured approach aimed at delivering cost-effective, well-organized, and high-quality services within a specific timeframe while addressing individual needs. Under this educational model, students with Deafblind receive intensive educational and therapeutic services with the assistance of special educators. The centre is equipped with accessible infrastructure such as lifts, ramps,

accessible toilets, handrails, and signages, ensuring an improved quality of life for the students. Additionally, the centre supports their rights and social participation.

### Community and Home-Based Program

Special educators, community workers, and physiotherapists provide essential interventions and educational services to Children and adults with Deafblindness at their homes. With the support of family members, we train these individuals to utilize their full potential. Through home-based services, we engage the entire



family in delivering necessary support to the child. Special educators spend more than two hours with the child, conducting educational activities that help them learn various life skills within their home and community environment.

### **Medical Assistance**

All Children and adults with Deafblindness receiving special services undergo medical assessments for their vision and hearing abilities. Based on these evaluations, they are assisted in obtaining disability certificates and accessing government benefits. Additionally, we conduct functional assessments for vision and hearing using an informal checklist developed by Sense International India.

### **Income Generation Activities (IGA)**

This initiative supports Adults with Deafblindness by providing them opportunities to start their own businesses independently or with family assistance. These businesses may include small beauty product shops, flour mills, incense stick packaging, file making, and more. Through this program, Individuals with Deafblindness can utilize their skills to earn a livelihood. Currently, several adults with Deafblindness are successfully generating income through this initiative.

