



# EARLY IDENTIFICATION & INTERVENTIONS FOR CHILDREN WITH DEAFBLINDNESS

Deafblindness is a condition in which a person may have combination of Hearing and Visual impairments causing severe communication, developmental, and educational problems (Rights of Persons with Disabilities Act 2016).





***“ The most beautiful things in the world  
cannot be seen or even touched  
- they must be felt with the heart. ”***

*Hellen Keller*

**CONCEPTUALISED AND DEVELOPED BY**  
The Spastics Society of TamilNadu @ Sense International India



## THE SPASTICS SOCIETY OF TAMIL NADU (SPASTN)

# THE ORGANIZATION –



### Celebrating Diversity & Enriching Lives .....with Dignity

The Spastics Society of TamilNadu (SPASTN) is a community based organization that endeavors to be a centre for excellence that empowers the well-being and inclusion of people with disability to achieve their fullest potential.

At the core of everything that SPASTN undertakes, is the passionate belief in the dignity of human life. It is for these underpinning values, SPASTN champions for the rights of disabled persons, the right to life, to information, to education, to health, to employment, to social security, to recreation leading to full participation.

### SENSE INTERNATIONAL INDIA (SII)

Sense International India founded in 1997 and formally known as Sense India. This is the first and only national level non-profit organization that works for persons with Deafblindness throughout India. Sense International India carries out this huge task effortlessly by partnering with like-minded organizations that work with persons with single disabilities.

As on date, Sense India is reaching out to 78000+ (direct – 14,594; indirect – 63,500+) persons with Deafblindness through 59 partners in 23 states and enable children with Deafblindness to receive education through Government's Samagra Shiksha scheme in the country. Sense India also extended its technical support to develop services for persons with Deafblindness in Bangladesh and Nepal to provide quality services for persons with Deafblindness.



### ACKNOWLEDGEMENT

The Spastics Society of Tamil Nadu is the Deafblind Regional Centre for the South (DbRC – South). As a Deafblind Regional Centre for Southern India we reach out and engage more grass root partner organizations to build their capacities based on the needs of persons with Deafblindness so that this could lead to establishing more services to meet the needs of persons with Deafblindness across Kerala, Tamil Nadu, Karnataka, Andhra Pradesh and Telangana in South India supported by Sense International India (SII) and funded by Azim Premji Philanthropic Initiative (APPI).

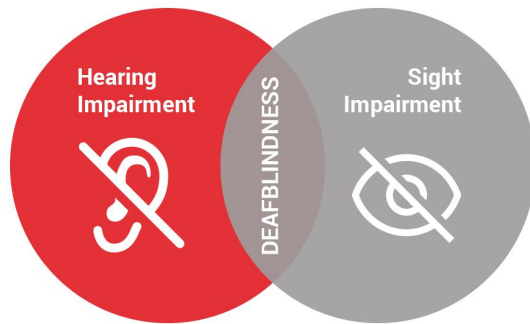
#### **Role of Deafblind Regional Centre for South (DbRC – South):**

- ✓ Number of potential grass root organizations identified across South – 50
- ✓ Conducted Southern Regional trainings on Deafblindness and Network meetings to build the capacities of the newly identified as well existing partner organizations across south.
- ✓ Conducted screening and clinical assessment of vision and hearing in the newly identified potential organizations with the support of Deafblind State Centre's (DbSC's) to identify and extend services to high risk persons with Deafblindness

#### **Awareness materials developed and published in the previous years:**

- ✓ The story of Nethran – Comic book on Deafblindness
- ✓ Posters on Deafblindness in the regional languages of south (Tamil, Telugu, Kannada, Malayalam and English)
- ✓ Brochures on High support needs of persons with Deafblindness in the regional languages of south

This manual has been developed in regional languages of south for better understanding of the rehabilitation professionals (team) on the aspects of the environment in conducting assessments and delivering interventions and understand the dynamic interactions between environment of the individual and his/her concurrent vision and hearing impairments.



## DEAFBLINDNESS

Deafblindness is a condition in which a person may have combination of Hearing and Visual impairments causing severe communication, developmental, and educational problems (Rights of Persons with Disabilities Act 2016).

### 5 WAYS IN WHICH DEAFBLINDNESS CAN LIMIT PARTICIPATION EXPERIENCES OF CHILDREN

#### INDEPENDENCE

Activities of daily living becomes difficult



#### COMMUNICATION

Difficulty in receiving and expressing

#### MOBILITY

Challenges in Orientation & Mobility



#### ISOLATION

Difficulty in making friends

#### ACCESS

Limited access to Education with required adaptations



## MAJOR CAUSES FOR DEAFBLINDNESS

- Prematurity and young for gestational age.

#### PRE - NATAL INFECTIONS:

- Syphilis
- Toxoplasmosis
- Rubella
- Cytomegalo virus (CMV)
- Herpes
- AIDS

#### NATAL AND POST - NATAL CAUSES:

- Asphyxia
- Trauma / accident
- Head injury
- Stroke
- Encephalitis
- Meningitis
- Tumours
- Metabolic disorders

#### GENETIC SYNDROMES:

- CHARGE Syndrome
- Usher Syndrome
- Down Syndrome (Trisomy 21)
- Goldenhar Syndrome
- Norrie's Syndrome
- Patau Syndrome (Trisomy 13)

#### MULTIPLE CONGENITAL ANOMALIES:

- Hydrocephaly
- Microcephaly
- Foetal alcohol Syndrome
- Maternal drug abuse



## CLASSIFICATION OF DEAFBLINDNESS

#### ONSET

- Congenitally Deafblind
- Congenitally deaf, acquired blindness
- Congenitally blind, acquired deafness
- Acquired Deafblindness

#### RANGE OF SENSORY LOSS

- Totally deaf with partial vision
- Totally blind with partial hearing
- Partial hearing and partial blindness
- Totally deaf and totally blind





## IMPORTANCE OF EARLY IDENTIFICATION AND INTERVENTION OF CHILDREN WITH DEAFBLINDNESS

The basic understanding between the principles of neuroscience science and method with which skills form in the early years clearly reinforces the importance of early detection and early intervention services for children who are identified as Deafblind. Starting quality early childhood services is very beneficial in maximizing the potential for growth and development, and support families and care givers. We do this by developing a partnership with the child, the family and other support networks and professionals.

### Families and / or care givers of children with Deafblindness can benefit from early intervention services in many ways:

- The outcomes in regard to developmental, social, and educational gains can be very tangible.
- Families can reduce feelings of isolation, stress and frustration that they may experience. A child who is vision and hearing impaired or multisensory impaired etc parents need to be taught how to work with child through day to day routines and interactions.

- It is important to work with families so that they can enable the nature of child's engagement with experiences, objects, people with whom the child is engaged. Mutuality, interaction and reciprocity is important and it should occur when the child is awake, feeding, changing when wet, etc.
- Help alleviate and reduce behaviors of concern by using positive behavior strategies and interventions.
- Help children with Deafblindness disabilities grow up to become autonomous in self - care, develop mobility to access services like child care, school, special schools etc.
- Reduce the future costs of health care needs, special education and rehabilitation needs.

### Early identification can help ensure:

- Proper treatment of vision and hearing loss.
- Communication needs are identified and addressed.
- Developmental and / or academic challenges are identified and addressed.





## SCREENING OF VISION AND HEARING

- Early and periodic screening of children for vision and hearing to identify children high risk to Deafblindness.
- Early and periodic childhood screening of vision and hearing support the achievement of optimal language, speech, socio – emotional wellbeing and educational outcomes.



## EARLY SIGNS AND SYMPTOMS OF VISION IMPAIRMENT

- Eyes move quickly from side to side (nystagmus), jerk or wander randomly
- Eyes don't follow your face or an object, or doesn't seem to make eye contact with family and friends
- Eyes don't react to bright light being turned on in the room
- Pupils seem white or cloudy rather than black
- Eyes don't appear straight but turn towards the nose or drift outwards



## JUST LOOK OUT IF AN OLDER CHILD IS....

- Sitting too close to the TV or holding books very close to the eyes
- Blinking repeatedly or squinting and closing one eye or the other
- Tilting their head to one side in an effort to see better
- Frequent eye rubbing during activities
- Light sensitivity and/or frequent headaches
- Losing their place while reading
- Avoids reading or engaging in close up visual work
- Irritation while doing visual work
- Poor hand-eye coordination



## SOME POSSIBLE SIGNS OF HEARING LOSS IN AN INFANT OR TODDLER

- Does not react to loud sounds such as cooker whistle or drop of a heavy utensil
- Does not seek out or detect where sound is coming from
- Does not engage in developmentally appropriate babbling, gurgling or experiment with making sounds
- May babble beyond the developmental age and is not able to produce understandable speech
- sounds such as “ba ba”, “ma ma”
- Does not react to voices, even when being held
- Ear is missing or not fully developed at birth



## SOME POSSIBLE SIGNS OF HEARING LOSS IN A SCHOOL-AGE CHILD

- Does not follow simple instructions, such as “get your shoes,” or multiple instructions in one go
- Observed to touch or pull people for calling attention to self or drawing attention of peers or teachers
- Exhibits frustration or behavior problems on account of frustration or inability to engage in two way communication
- Is falling behind with speech and communication skills
- Cannot understand oral communication unless facing the speaker
- Does not turn or identify to where sounds are coming from
- Exhibits exhaustion during school or after school hours due to strain of attentional effort to understand speech
- Exhibits signs of behavioral problems or social difficulties
- Experiences problems keeping up at school or grades slipping



## FUNCTIONAL VISION AND HEARING ASSESSMENT

- Functional Vision and Hearing Assessments refers to the way in which an individual uses whatever vision and hearing he or she has in everyday life.
- Functional Vision and Hearing Assessments, as well as strategies improve the use of hearing and vision.



## EARLY INTERVENTION OF CHILDREN WITH DEAFBLINDNESS

- Early Intervention describes the services and supports that are available to babies and young children with developmental delays and disabilities and their families. They provide points of entry for the child, family and the community.
- The nature of early intervention for children with Deafblindness has to include bio-psychosocial factors that interact and interplay with the nature of impairment. This in turn affects the way a child can participate in activities given the personal and environmental context. E.g.: A child who has usable vision or hearing gives us the entry points for intervention which in turn will determine the trajectory of development.
- The International Classification of Functioning (ICF) model in 2001 gave us a framework that can drive planning, monitoring progress and outcome that optimizes the child and family's potential.

## SIX “F” Mantra – for THOUGHT and ACTION

FUNCTION	FAMILY	FRIENDS
FUN	FITNESS	FUTURE

1

### The First ‘F – Word’: FUNCTION

**I might do things differently but I can do them.  
How I do them is not important. Please let me try..!**

- Function refers to what people do. For children ‘Play’ is their ‘work’.
- Functioning refers to execution of a task or action by an individual in the best possible way he or she can do in everyday activities at home, school and neighborhood. Experiences can give them practice over time.
- On a resonance board a child who does not normally use vision may look to see what is tapping or rocking on the board or may use vision to guide arm or leg movements to produce interesting feedback again.



- A child who dislikes using his or her hands to touch things might reach out to make sounds and vibrations happen again.
- A child with Deafblindness can perform an activity or task using his/her residual vision and hearing with required adaptations / modifications.  
E.g.: Use of assistive devices such as glasses and hearing aid to make use of the residual vision and hearing for reading and writing.
- Performing an activity by anticipation.  
E.g.: A child who has to carry out a purposeful action such as press or pull or strip for engaging with the toy or able to build a 2 or 3-piece bridge blocks with or without support.



2

### The Second ‘F – Word’: FAMILY

**They know me the best and I trust them to do what's best for me.  
Listen to them. Talk to them. Hear them. Respect them.....!**

- Family – centered services in which families are considered as partners enables us to see that engagement with parents, respect, continuity of care and informing people appropriate act as key elements of service values by families.
- The more we involve families, parents or care givers not only provide their intrinsic knowledge and information about the child but also helps us in knowing the family needs for counseling and training needs.
- **Parents as Self - Advocates:** Engaging families can help build their capacities and develop the skill of advocating for their child. The advocacy skills are essential across the life span of child as the needs of the child will evolve over the years with the support of the family.
- Many parents who have children with Deafblindness may require emotional support and guidance to work with child to develop mother child bonding or attachment. Hence role of local parent group is relevant to build support system which helps all the families around in overcoming challenges.
- We have to develop competency in the mother so that she is able to participate and share areas of focus for Individualized Educational Plan (IEP).

3

### **The Third 'F - Word': FITNESS**

**Everyone needs to stay fit and healthy, including me.  
Help me find ways to keep fit....!**

- The fitness of children with disabilities is a component of body structure and function and has been a neglected aspect of childhood disability.
- We need to understand what makes it easy or hard for children and adolescents with disabilities to become and to become fit and to stay physically active.
- Exercise programs and fitness training with better recreational opportunities can be beneficial in children with disabilities to stay physically active.  
E.g.: Fitness activities: Running, walking, aerobics, gymnasium, etc.  
Community activities: Dance, Martial arts, etc.  
Sports: Swimming, throw ball, participating in school sports, special Olympics, etc.
- This can reduce physical, social and psychological isolation.

4

### **The Fourth 'F - Word': FRIENDS**

**Having childhood friends is important.  
Please give me opportunities to make friends with my peers...!**

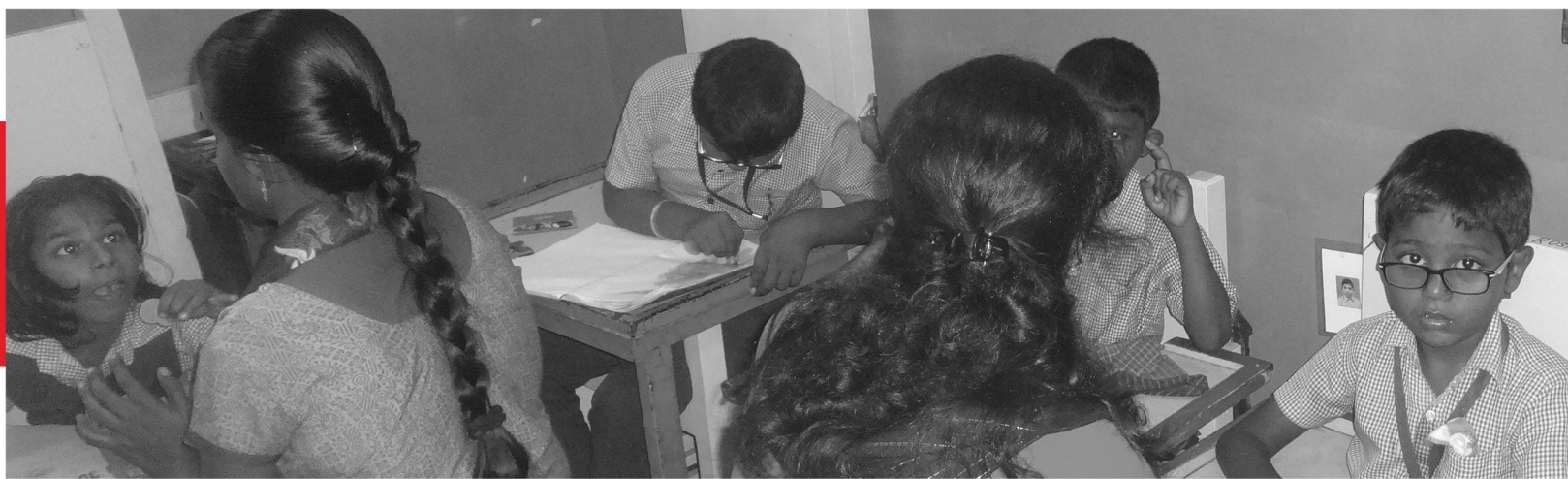
- Socialization is a serious business. Situations and scenarios have to be structured and planned so that the child can develop concept of self, interpersonal and play skills and carries out task independently.
- Children with Deafblindness need to be involved in peer group activities for developing relationships and to be aware of sex health education once the children reach adolescence and young adulthood.

5

### **The Fifth 'F - Word': FUN**

**Childhood is about fun and play. This is how I learn and grow.  
Please do me the activities that I find the most fun....!**

- We all know that children with Deafblindness and/or multiple disabilities spend more time and effort in doing the daily activities than their sighted peers. A child with vision and hearing can easily anticipate daily routines through sights and sounds associated with it. But the same can be traumatic for a child with sensory loss as they see them as unpleasant surprises. Every child with vision and hearing loss is different and the way they make use of the vision and hearing they have and the way they learn to use it. So parents and professionals can together work to know what intrinsic interests the child shows in activities that are either tactile, auditory or proprioceptive etc. Once we understand the nature, quantity and quality of experiences the child is willing to accept and tolerate can then set the tone to make activities around it "FUN". Once the FUN ZONE is understood we can then hold and expand the nature of activities the child is willing to explore.  
E.g.: All routine activities of daily living are excellent opportunities to make activities fun with the children.
- Through play the child can learn a great deal and it is much more than mere play.
  - ✓ Trust and anticipation that certain things will always occur.
  - ✓ How to make things happen.
  - ✓ The power of making choices.
  - ✓ Better understanding of the world.
  - ✓ Communication in its many different forms.







6

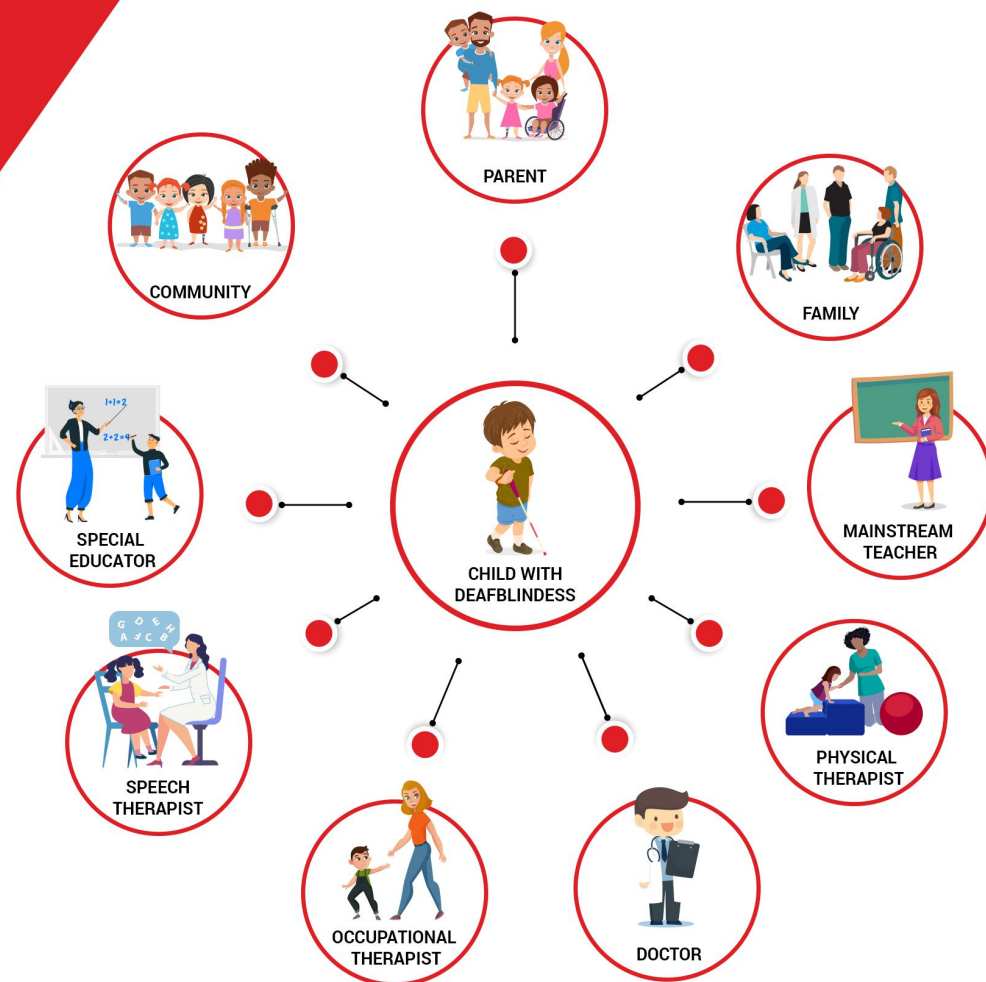
### The Sixth 'F - Word': FUTURE

I will grow up one day. So please find ways for me to develop independence and be included in my community....!

- Child development is all about future. Achieving current skills in the best possible manner across all domains such as gross motor, fine motor, socialization, communication, orientation and mobility, etc shall enable the child and the family to be motivated about the possibilities as the future unfolds.
- When families think about the future, they can also consider various services and transitional options. E.g.: The child may have access to integrated or inclusive environment as a transitional pathway from the current services. When families have thoughts about the future it gives service providers an indication that parents can be engaged and involved in the child's development for a desired future.



## TRANSDISCIPLINARY TEAM WHO WORK WITH CHILDREN WITH DEAFBLINDNESS



## COMMUNICATION OF PERSONS WITH DEAFBLINDNESS



There are many different ways that Deafblind people communicate, rather than one standard method. The mode of communication depends on the personal preference of the persons with deafblindness and the nature of sensory loss whether it is congenital or acquired. Many people who become Deafblind over time prefer to adapt to the way in which they are used to communicate, rather than learning a new method.

**Some common communication methods are:**



### SPEECH

Many persons with Deafblindness are able to speak verbally. This is because they probably would have learned to talk before their sight and hearing deteriorated.

Lip reading is a method of identifying words by watching the shape of speaker's mouth when they talk. It is often used alongside speech.

### LIP READING

### SIGN LANGUAGE

Sign Language is a visual communication method that uses hand and body - based gestures instead of spoken words.

Finger spelling is the representation of the letters of the writing system, and sometimes numeral systems, using only the hands. These manual alphabets have often been used in education, and have subsequently been adopted as a distinct part of a number of sign languages.

### FINGER SPELLING





*We don't need to see or hear in order to touch the world around us.*

### **MAKATON OR KEY WORD SIGNING**

Makaton is another visual language using signs and symbols. It is designed to support spoken language and the signs and symbols are used with speech, in spoken word order.

### **TACTILE SIGN LANGUAGE (SYSTEM) FOR DEAFBLIND**

Tactile sign language communication method where individual letters and entire signs are signed on to the hand of the Deafblind person so that you can spell words. This is often used by people who have little or no sight or hearing.

If a Deafblind person has some usable vision then he/she would follow signs by holding the signer's forearm or wrist and uses his/her eyes to follow the signs visually. Having the connection of using vision and touch together means the signs stay within the visual frame and are effectively 'tracked'.

### **TRACKING**

Probably the easiest Deafblind tactile language to express – the block alphabet uses English capital letters, drawn on to the palm of the Deafblind person.

### **PRINT ON PALM OR BLOCK**

### **HANDS ON SIGNING / CO – ACTIVE SIGNING**

Hands on signing is a tactile derivative of Sign language where you gently hold the hands of the child and teach him/her to perform a particular sign.

### **TADOMA**

Tadoma is a way of receiving communication by placing the hands of a Deafblind person on someone's throat, lips or cheeks. Practiced users will be able to identify words by feeling lip movements and vibrations.

If a Deafblind person has a reduced field of vision then you might find visual frame signing is useful. This is where the communication partner signs within a smaller area to ensure all of their signs stay within the field of vision.

### **VISUAL FRAME SIGNING**

This is less of a communication system and more of a means to refer to an activity or event. Objects of reference can be really helpful in developing language. E.g.: A parent of a Deafblind child may use a sponge to tell their child that its bath time or use a spoon and glass to indicate eating and drinking.

### **OBJECTS OF REFERENCE**



## CONCLUSION

The Manual on Early Identification and Interventions for children with Deafblindness has been conceptualized and written keeping in mind International Classification of Functioning (ICF) as a unifying model in rehabilitation of practice across inter-disciplines to drive planning, monitoring progress and outcome that are person and family centric. It promotes care/intervention that is person-centered, holistic, organically sustainable across domains including (but not limited to) home, child care centers, schools, recreational, or other settings.

This versatile framework takes into context the bio-psychosocial factors as the interplay of impairments, activities and participation which is mediated within personal and environmental context which helps teachers/therapists to look beyond their own areas of practice and communicate across disciplines to promote functioning of persons with Deafblindness. Such an approach helps to bridge the gap between current repertoire of competencies of the person and his environment. Special education teachers have to bridge the void between capacity and environmental context leading to inclusive practices and to enable participation in socially valued activities when planning Individualized Educational Plan.

This manual enables the rehabilitation team and families of persons with Deafblindness to engage, work and advocate for removal of environmental barriers and ensure provision of appropriate resources to provide opportunities and to facilitate full participation for persons with Deafblindness in the society.

## REFERENCES

- <https://newzhook.com/story/20529/>
- <https://slideplayer.com/slide/13414545/80/images/8/Major+Causes+of+Deaf-Blindness.jpg>
- <https://slideplayer.com/slide/4723383/>
- <https://raisingchildren.net.au/disability/guide-to-disabilities/assessment-diagnosis/vision-impairment>
- <https://www.cochlear.com/us/en/home/diagnosis-and-treatment/diagnosing-hearing-loss/signs-of-hearing-loss-in-children>
- <https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability>
- <https://www.nationaldb.org/info-center/early-interactions-factsheet/>
- <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2214.2011.01338.x>
- <https://deafblind.org.uk/information-advice/living-with-deafblindness/communication/>



# GET IN TOUCH

## Deafblind Regional Center for South (DbRC - South)



### **The Spastics Society of TamilNadu (SPASTN)**

CSIR Road, Taramani, Chennai - 600 113.

**Royapuram Branch:** No.34, Veera Kutty Street,  
Old Washermenpet, Chennai - 600 021.

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☎ 044 - 22541651, 22541542, 22541133

🌐 www.spastn.org

## Deafblind State Centre's (DbSC's):



### **Holy Cross Service Society**

No.3, Ettupattai compound, Behind Government Hospital,  
Puthur, Trichy - 620 017.

Tamil Nadu

✉ 0431 - 2771544

☎ holy.cross.servce.society@gmail.com



### **Uma Educational & Technical Society(UETS)**

(Voluntary organisation for Development of Inclusive society)

# 4-54, Uma Manovikasa Nagar, Vakalapudi Panchayat,  
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### **Kottayam Social Service Society**

Chaithanya Pastoral Centre

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### **Mathru Educational Trust for the Blind**

4th Cross, Yelahanka 4th Phase,

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