



**Challenges faced by  
Children with  
Vision Impairment**

# **Difficulty in detecting low/partial blindness and lack of awareness on appropriate intervention**





**“Studies worldwide show that approximately 40% of childhood blindness is avoidable or treatable”.**

World Health Organization,  
Vision 2020

# Impact

- For children who have vision loss that cannot be clinically treated, low vision devices and early rehabilitation can be a crucial factor in holistic growth.
- Nearly 75% of a child's early learning comes from vision. Hence, early onset visual loss can have profound consequences on a child's motor, social, emotional, and psychological development





**Parents are not made aware to be attentive to the visual skills of the child and watch out for early signs of blindness such as :**

- Is my child responding to visual stimuli?
- Is he/focusing properly?
- Is he/she looking directly at others in the eye?

# Challenge for parents

- In most cases in India, getting to know of the early signs of blindness visual skills that the child is not responding to, is a big challenge for parents.
- If the child is completely blind, parents get to know it within 5-6 months of birth. Early detection of partial blindness however, takes a much longer time and is more difficult.



## **This lack of scientific knowledge about the impact of blindness on early development can be attributed to:**

- Parents of Blind children don't have access to doctors
- Use of inadequate assessment procedures done by the medical center where child is born
- Lack of accurate information given to parents by doctors



“There has to be a proactive screening at the grass root level to identify the problem”.

In US, when a child joins school, is mandatory to get a certificate from the ophthalmologist saying that the child can see well. When we do school camps, we found children in 12th standard who had a high visual disability. Naturally these children weren't performing well.

**- Dr. Vasumathy Vedantham**

The first step in early intervention is to establish the origin of the visual impairment, though the spectrum of visual problems in infancy is very broad. Treatment should begin as early as possible in a positive emotional setting that enhances the child's motivation and relationship with caregivers.

**~ Shalini Mathew , NAB Delhi**

# Need for Early Intervention

In medical facilities, infants are unable to verbalize their complaints to doctors and history from parents and care takers may lack important details. The first year of life is the time when the visual system develops, and binocular vision is formed. If a visual deficit at this age is not treated in a timely manner, amblyopia and permanent visual deficit can occur.

**Hence, early diagnosis by parents and prompt treatment becomes even more essential.**





**When a parent realizes that their child is visually impaired, they need to be provided with a good understanding of questions like :**

- What does this mean for my child?
- How will this affect my child's development?
- What do I need to do now?
- What kind of treatment and interventions I should be considering?"

# This is Abhay...

**3 years, Male, Vision Impaired- Severe, New Delhi**

Abhay was born with no vision. Though he has perfect looking eyes, the way he behaved and used his eyes gave a clear indication of a problem with the way he saw, even before he turned 6 months old. Abhay belongs to a very poor family. His father is a driver and mother works as a house help in several houses in the vicinity of their house. He has an elder brother who is very interested in sports and the parents spend most of their free time and resources in helping him pursue his hobby as a future profession.



# What happened ?

Within 6 months of Abhay's birth, it was obvious to the family that he had no vision in his eyes. His mother was very weak and mostly unwell when she was carrying Abhay. Doctors believed that malnutrition could be the reason for his blindness. His disability was neither diagnosed during birth nor during the several visits made for vaccinations. It was only when the family had a doubt and took Abhay for specific eye check-up that the doctor confirmed his blindness. Even post confirmation, doctors only advised giving him nutritious meal, doing eye exercises and, prescribed some eye drops. Despite of repeated questioning, Abhay's parents were not counselled on how they could assist Abhay.

**Until very recently they did not even know about the existence of DIECs (District Early Intervention Centers).**

- Due to hectic work hours, both the parents switch the television on and leave Abhay in the room. His mother keeps visiting after every few hours and tends to his needs
- His brother is in school most of the day and comes back home only in the late evening after playing with his friends. At night, when the whole family is together, conversations are centred around daily chores or Abhay's brother Prince. Abhay is mostly a silent spectator whose presence can go totally unnoticed
- Blindness coupled with lack of any kind of intervention and hours of sitting on the bed and watching TV has caused Abhay's legs to become very weak. This along with his blindness results in him getting very nervous and stumbling when he is asked to stand up.
- Due to lack of activity, he remains constipated for almost a week at a stretch. He has lost his appetite and become very weak in the process.
- **Due to limited communication with the family , he is mostly non- verbal. He repeats the songs which he hears on TV.**



- When his parents took him to get his disability certificate made , the doctors were not sure if he had multiple disabilities or the lags were because of lack of intervention. His parents heard the same comments when they tried to enrol him in a special school for blind. Being a residential school, they only enrol children with vision impairment .
- The parents have been advised physiotherapy and enrolment in an early intervention program but this requires time and commitment which comes at the cost of their daily work.
- Result being , Abhay, who's disability was diagnosed quite early and could have benefitted from a properly designed intervention program which looks into his cognition, physical ,social-emotional, adaptive, and communication/ language needs, leads a silent life in complete isolation.
- **There are several such Abhay's in the urban slums and rural areas of India whose parents cannot afford the indirect costs of early intervention and hence succumb to their disability.**



Challenges faced by children  
with Vision Impairment

# This is Shaktivel...

**17 years, Male, Blind, Chennai**

Shaktivel has a degenerative eye problem. Though detected early nothing could be done to maintain his residual eye sight. In his early childhood days he could read bright coloured text in big font. Over the years he has lost his sight completely. He has a sighted brother who is 2 years younger to him. His father works in a courier company. His family has been very loving and supportive. His mother /father always accompany him to any new place and his brother includes him in all extra curricular activities. He bonds very well with his family with no feeling of exclusion.



# What happened ?

- Shaktivel was born at a governmental hospital in Chennai. When he was born he was declared fine and healthy. When he was four months, his mother found that there is rapid involuntary movement of his eye. They got his eye tested. Doctors informed them that there was a problem with his retina and that it is a degenerative condition and nothing much can be done in the form of treatment. Shaktivel had some vision. He could see bright coloured objects and even big letters. That is how he learnt English alphabets and he can even sign his name now. However, this degenerated over time.
- His mother put him in a government school where he completed his LKG and UKG. He was taught everything auditorily. The teacher at the school advised the parents to move him to a blind school as the teaching and training methodology there was much better for his condition. They also referred her to a counsellor who guided her
- She then admitted Shaktivel in Little Flower Convent where he was taught Braille for the first time. Along with the child, the school taught Braille to the parents as well. For the first time she was hopeful about here son's life.

“When I came to know that Shaktivel will eventually lose his sight, I was very upset and even contemplated suicide . My employer read a news article about a mother who committed suicide thinking that her two children would get her eye upon her death without even realizing that her children did not require an eye transplantation. **My employer was the one who counselled and motivated me. She helped me a lot”**

**- Shaktivel’s mom**



# This is Anand...

## Male, Vision Impaired- Severe, Chennai

Anand was born in Tirupattur and was doing fine. His parents noticed a lag in his development when he at around 1 year of age. He would not pick up ball if it was thrown down nor would he turn properly when he was called and additionally he had a squint. They took him to an eye hospital in Chennai. Upon testing they found that he had fewer optic nerves. Parents were informed that as Anand grows up it would become normal. In the meantime they were advised to give Anand nourishing and nutritious food. They did not recommend any treatment nor was Anand given any assistive devices.



# What happened ?

They went to the same hospital on a yearly basis. Initially he had some vision ( he used to be independent and could even ride a cycle) and did his schooling in a mainstream government school (up to 1<sup>st</sup> standard) along with his cousins. He was doing fine academically . The only noticeable challenge was his illegible handwriting. Teachers advised the parents to consider special school for him

In the meantime Anand's eye sight was deteriorating. Yearly check up was not proving to be of any help. Despite giving him healthy food there was no improvement. They did not get any clarity on what needed to be done. Hence, they then took him to another hospital to get tested (by now he was 10 years old). Doctors at this hospital informed the parents that Anand has weak optic nerves and that there is no specific treatment for it. During this time he had missed one year of school. Additionally 1<sup>st</sup> standard teachers found that he had hearing problems . Since then he has been wearing a hearing aid as well.

His parents have since then decided to not give up and focus entirely on giving him a good education. His father is a tea vendor ho supports him in all his needs.

# Wish-list for Early Intervention for visually impaired children and their families

**Integrated Approach** – Evaluating all developmental areas - cognition, physical , social-emotional, adaptive, and communication/ language

**Individualized Approach** – Mandatory and subsidized services to develop Individualized Family Service Plan which are assessed and evaluated regularly with the support of trained professionals for visual impairment

**Extended Approach** – In addition to support, knowledge, and strategies for assisting the child , families acquire support for tackling their own Individual needs.

**Collaborative Approach-** Institutions and experts act coherently. Families are given a profound insight into the child's special needs

**“Childhood blindness is the second largest cause of blind-person years, following cataract.**

Failure to detect and appropriately manage disorders of vision in early childhood may have long-term consequences, relating to development of normal vision, self-confidence and realizing the true potential of a child. ”



# Some possible solution ideas:

## **1. An application with checklist for parents to assess their child's visual skills.**

E.g. A simple 10-point questionnaire in the local language to assess whether the child has a VI –

- Does your child stumble and fall frequently
- Does the child hold the picture book close to his eyes, etc
- Based on assessment, provide numbers and addresses of nearby clinics and doctors they can visit for a consultation



## Some possible solution ideas:

### 2. A platform/application with information for parents regarding:

- How to screen for and identify risk factors or behavioral indicators of potential visual impairments
- Various eye condition and the treatments available along with approximate cost and referrals to places where it can be accessed
- How to assist the child in building his confidence and skills to interact with the environment
- How to engage a child at home incl. games that would be suitable for the VI child along with places it can be bought from



## Some possible solution ideas:

**3. Processes in place for Medical Professions to carry out comprehensive multi-disciplinary assessment to enable correct diagnosis. For e.g.** vision screening ,medical ophthalmologic ,orientation and mobility evaluation, developmental evaluation and assessment

**4. A task-based detection game or a toy for children aged 0 -1.5 years which can be an indicator for various disabilities.**To be disseminated to Parents, Paramedics and Pediatric Doctors. In case of detection, this game can be combined with an App that acts as information packet for parents about what should be done after detection and who to contact. Later it can act as a database of doctors, special/inclusive schools, organizations, rehab centers, etc.

# Helpful Readings

1. Assistive Tech for screening : Wave front technology, Refraction Tests, Digital Retinal Scans, Slit-lamp Exam, 38-plate Colour Blindness Test
2. Severe Visual Impairment and Blindness in Infants: Causes and Opportunities for Control  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3119278/>
3. Causes of childhood blindness in the northeastern states of India  
<http://www.ijo.in/article.asp?issn=03014738;year=2008;volume=56;issue=6;spage=495;epage=499;aulast=Bhattacharjee>
4. Vision Screening of School Children by Teachers as a Community Based Strategy to Address the Challenges of Childhood Blindness <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4866147/>
5. Formative Research Report on RBSK 'From Survival to Healthy Survival', July 2016  
[https://nhm.assam.gov.in/sites/default/files/swf\\_utility\\_folder/departments/nhm\\_lipl\\_in\\_oid\\_6/menu/schemes/Formative\\_Research\\_Report\\_on\\_RBSK.pdf](https://nhm.assam.gov.in/sites/default/files/swf_utility_folder/departments/nhm_lipl_in_oid_6/menu/schemes/Formative_Research_Report_on_RBSK.pdf)
6. [Blencowe, H](#); [Moxon, S](#); [Gilbert, C](#); (2016) Update on Blindness Due to Retinopathy of Prematurity Globally and in India. Springer Verlag
7. <http://researchonline.lshtm.ac.uk/id/eprint/3172479>