

## Visual function assessment, ocular examination, and intervention in children with developmental delay: A systematic approach - Part 2

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In India, there is increasing number of children with development delay and vision impairment with or without additional disabilities due to prematurity, brain damage, cerebral palsy, or genetic syndromes. Despite initiatives from Government of India, early intervention for these children remains a challenge across the country due to lack of trained professionals and appropriate resources. This paper describes the developmental screening tools, intervention aspects including Individualized Education Plan, procedures for handling children with cerebral visual impairment, team approach, and guidelines derived from the inputs of experts in vision rehabilitation centers of premier eye institutes in India

**Key words:** Cerebral visual impairment, developmental delay, early intervention

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An estimated 200 million children in the world are disabled and a majority of them live in low- and middle-income countries.<sup>[1]</sup> In India, an estimated 10% of the 15 lakh newborn are affected by developmental delay. If not intervened early, this may lead to permanent disabilities with regard to cognition, hearing, and vision.<sup>[2]</sup> Families of children with disabilities suffer significantly from stress and emotional trauma as they lack knowledge on important aspects of their child's future such as, knowledge on child's health condition, treatment and intervention possibilities, people who should be approached for help, types of services available, educational opportunities, etc.<sup>[3]</sup> Toward addressing this issue, the Ministry of Health and Family Welfare, India, launched a preventive program Rashtriya Bal Swasthya Karyakram (National Child Health Program) in 2013 with a purpose of early screening for birth defects, diseases, deficiencies, and development delays including disabilities in children between 0 and 18 years followed by intervention to such children through district early intervention centers.<sup>[4]</sup>

Despite this initiative, early access to intervention is continuing to be a major challenge in India due to the following reasons; lack of awareness among families and professionals on the importance of early intervention, nonavailability of trained professionals in all development

domains, limited tools, and resources to cater to the entire population, lack of access to services for the children from rural areas, as most early intervention centers are urban based.

The study by Salt has shown that vision impairment has close association with children born preterm, suffered brain damage or cerebral palsy (CP) and who have congenital cerebral anomalies or other genetic syndromes that may predispose to ocular anomalies.<sup>[5]</sup> Cerebral/Cortical visual impairment (CVI) is frequently found in children patients with CP in addition to ophthalmological disorders.<sup>[6]</sup>

The procedures for assessment of visual functions and ocular structure/eye health have been described in our previous paper.<sup>[7]</sup> As a follow-up of examination, this paper describes the intervention aspects of children with developmental delay and vision impairment with and without additional disabilities. This paper explains the key procedures to be followed in early intervention, beginning with the importance of parent and family counseling to approaches to intervention and recommendations, with the aim of guiding the clinicians and rehabilitation professionals in incorporating these in their practice.

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## Interventions for Children with Developmental Delay and Vision Impairment

Early intervention program for children with developmental delay and vision impairment includes parent and family counseling, support services, developmental screening protocols, team approach to plan, execute and monitor an individualized education program.

### a. Parent And Family Counselling

The early intervention can be effective only when the parents and family accept the child's condition. Therefore helping the parents cope with their emotional and psychological distress should be the first and foremost important service. The first session should provide emotional support, information about the visual condition, visual prognosis, educational and vocational possibilities, success stories of persons with similar history, etc. Studies<sup>[3,8]</sup> have shown that parenting a child with disability may cause a significant disturbance in the family. A sense of guilt, high psychological distress, breakdown, mental illness, split partners, suicides, etc., are more common in families having a child with special needs. However, an effective counseling can help to nurture the emotional well-being of the family. Multiple sessions of individual and family counseling at different intervals will help them cope with psychological issue.

It is important to involve family members in the rehabilitation process at all stages from designing the rehabilitation plan to providing the services. It is evident that, "Parent-to-parent peer support has a positive influence on parents' levels of psychological distress and their ability to cope with being a parent of a child with a disability".<sup>[9]</sup> Toward this effort, peer support program for families can be organized as it gives a great opportunity to share ideas to handle the children and build the motivation to move forward.

### b. Support services

There are several welfare initiatives and schemes by Indian Government to support the empowerment of Person with Disabilities (PwD) and their families. The National Trust schemes help the children with multiple disabilities in accessing early intervention services, day care, respite care and health insurance for which they are guided by the rehabilitation centers.<sup>[10]</sup> The education allowances for the persons with vision impairment include books, scholarship, reader, permission to use assistive devices, large print question paper, scribe for writing examination, extra time in the examination, substituting visual questions, exemption from third language, etc.<sup>[11-13]</sup> Many states in India, for example, Telangana, New Delhi and West Bengal provide disability pension to children irrespective of their age.<sup>[14]</sup> Although the schemes and concessions are fruitful, the cumbersome procedures limit many potential beneficiaries in accessing these facilities. One can avail these concessions by producing the mandatory documents of disability certificate and disability identity card; however, the complicated procedures to get these documents make many PwDs to forgo these facilities. Hence, guidance and assistance on completing the protocol should be explained to the parents and families.

### c. Developmental screening and monitoring

Vision impairment can interfere with multiple domains of early development. Delayed developmental milestones

can further have a negative impact on an infant's ability to recruit or use their vision effectively. It is important to use objective, well-researched tools to determine the rehabilitation goals, intervention plan, and monitor the effectiveness of the program.<sup>[15]</sup> No single tool allows the tester to get the complete picture of development across multiple domains of these children. The following are some of the commonly used tools though not validated in India, 1) The Oregon Skill Inventory for Visually Impaired & Blind Pre-school Children is designed for 0–6 years and this assessment can be carried out by parents, teachers, vision specialists, counselors or therapists in the home or in the classroom setting.<sup>[16]</sup> 2) The Callier-Azusa Scale is designed for use with deaf-blind and multiple disabled children from 0 to 8 years, must be administered by individuals who are thoroughly familiar with the child's behavior.<sup>[17]</sup> 3) Assessment of characteristics and ranges in children with CVI should be done by the professionals with significant experience in the field of CVI and this is meant for the age group of 6 months to adulthood.<sup>[18]</sup> 4) Inventory for Visual Perceptual Difficulties is designed for children with CVI and this question inventory must only be administered by professionals who are experienced in working with children with vision impairment due to damage to the brain.<sup>[19]</sup> This software provides a report with a list of difficulties and also suggests strategies for managing the same.

The first two scales focus on vision, cognition, speech & language, social, emotional, compensatory, and daily living activities of children with vision impairment & additional disabilities. The later scales are meant for children with CVI. These scales can be used in Indian population, using the material familiar to the child without changing the meaning.

Assessment of all developmental areas is recommended to plan individualized rehabilitation/education. Latency in responding to stimulus is expected in children with CVI and multiple disabilities hence the rehabilitation professional should have the patience to elicit response from such children.

### d. The Professional Team

An interdisciplinary approach is recommended to provide early intervention in which therapists conduct assessment in developmental areas in their respective specialization and present the findings and management plan to the team. The entire team along with the parents discusses the goals and modifies them before incorporating into Individualized Family Service Plan (IFSP). This plan recognizes the immensely important role of parents, their knowledge, beliefs, worries, abilities, stress, and challenges in impacting the environment available to the infant and therefore the intervention itself. The kind of professionals to work with the child depends on the type of disabilities and the skills needed to be learnt by the child.<sup>[20]</sup> The recommended members of early intervention team include part time or full-time professionals to work along with the parents are vision rehabilitation professionals, vision therapists, rehabilitation counselors, special educator, orientation and mobility instructor, optometrist, low vision therapist, physical therapist, occupational therapist, speech and language therapist, and social worker.

### e. Referral to Inclusive or Special schools

When the child acquires school readiness, he/she will be referred to inclusive or special school with a letter of recommendation stating the needs of the child. Inclusive

education admits children with any disability and who can manage their education and mobility with assistive technology and training in special skills. Ideally, all children should learn along with their peer group. However, thoughtful planning and adequate supports are required to ensure that children receive adequate instruction in areas that build their core skills while at the same time enjoying the benefits of learning along with their peer group. Learning along with peers in truly inclusive environments gives children a chance to learn skills and develop relationships that will support them through the rest of their lives. Special schools admit children with an identified disability who need specially designed instruction to meet his or her needs and enable them to access the general curriculum at a pace and in ways that best support their learning. The loss of natural social environments and challenges should be compensated for in individual plans created for the child and family. The match between the priorities as determined through the IEP process, and the facilities actually available are the final determining factors in the choice of educational settings. Some children may start with special service centers and then move into inclusive settings. Others may start with inclusive settings and then transfer to special centers as they grow older.

#### **f. Individualized Education Plan (IEP)**

Measurable annual academic goals need to be set for children based on their functional vision. The professionals involved in the educational activities should plan IEP toward achieving these goals and evaluate the outcome periodically. Based on the progress in academics further modification in goals should be recommended. The IEP should have the results of functional vision and visual functions assessment, recommendations for education, educational placement in special or mainstream classrooms, level of support or accommodations needed, learning media recommendations on Braille, large print, and audiobooks or combinations. It will also include preferred print size, contrast, and working distance, field of view for presenting materials, environmental supports—light, blocking visual, auditory or other distractions, appropriate seating arrangement considering the remaining functional vision, assistive devices like magnifiers, embossed rulers, pointers.

Specific suggestions to improve functioning in other domains such as communication, posture, mobility or behavior support, recommendations for training in use of Assistive Technology devices, Braille and abacus, specific long and short term rehabilitation goals for education and job placements are also incorporated in IEP.

Follow up: Periodic follow up should be encouraged to monitor the child's educational performance in the classroom environment. It is important to check whether the child is comfortable in using the recommended assistive device, whether the teachers are encouraging the child to use the same, whether there are any specific complaints such as difficulty in copying from the blackboard and notebook, inadequate writing speed, errors, inability staying on the line while writing, etc., are some of the very important factors to be checked and resolved during the follow-up visits. It is mandatory to carry out periodic re-assessment of functional vision and visual functions as the visual needs and demands change eventually in some children.

#### **g. Intervention for children with CVI**

CVI, optic nerve abnormalities, or retinal disorders are the main causes of vision impairment in children with developmental delay and knowledge about the visual problems is important in resource planning.<sup>[21]</sup> Children with CVI may have a medical history of neurological impairment due to asphyxia, cerebral hemorrhage, infection of the central nervous system and/or trauma and they are diagnosed by ophthalmologist and/or neurologist.<sup>[22]</sup>

##### *Characteristics of children with CVI*

Children with CVI have specific behavioral characteristics.<sup>[23]</sup> "Looking" should not be interpreted as "understanding". Hence the professionals need to understand the characteristics of these children.<sup>[24]</sup> Strong color preference, need for movement to elicit visual attention, visual latency and visual field difficulties, difficulties with visual complexity, light gazing and non-purposeful gaze, absent or atypical visual reflexes, difficulty with visual novelty, absence of visually guided reach are the commonly showed characteristics of children with CVI.<sup>[18]</sup>

##### *Guidelines to handle children with CVI*

These guidelines are drawn based on clinical and rehabilitation practices from the centers practicing CVI across India. Some children are easily overwhelmed with multiple sensory inputs—reduce visual and auditory features that may distract visual attention. Some children cannot attend to more than one thing at a time—they will benefit from single sequential presentations. Most children need to first understand what they are being asked to see—describe the object or scene and help the child make sense of it by pointing out key features that they are familiar with. Use objects that are easily visible to the child, especially when introducing new information. Children may need multiple exposures to fully absorb various visual aspects of an object or activity. Recruiting and sustaining visual attention and understanding what they are seeing is very tiring. Stay alert to signs of visual or general fatigue. Plan sessions that are well within this period. Positioning plays a very important role in helping children recruit vision and sustain attention. Work with a therapist to ensure optimal positioning for the task planned.

Evidence suggests beginning the intervention in the early years of the child is very critical. Neural plasticity is greatest in the first years of life but has been shown to continue throughout life, albeit at a slower pace.<sup>[25]</sup> Similarly, much of the development of visual capacity occurs in the first months slowing significantly as the child grows older. The same is emphasized in other studies that development of acute vision occurs in an early period from birth to 10 months of age and a slower development occurs from 10 months to nearly 10 years.<sup>[26,27]</sup> The findings of these studies suggest the early intervention at the critical period of visual plasticity to improve the visual functioning of children who sustain serious brain injury during their infancy or early childhood.

With infants and young children with CVI who present as profoundly visually impaired, we enter the intervention planning process, knowing that many are simply unable to recruit visual attention or are overwhelmed because they are unable to organize their visual inputs. Positive outcomes have been shown by managing the demands of the visual and

sensory environment as well as the demands on their other systems making it easy to see and providing activities that are motivating, and have a strong basis in real experiences.<sup>[28,29]</sup> There are several suggested systems of classification based on vision.<sup>[18,30]</sup> However, as different activities like walking, communicating, and reading place significantly different demands on visual functioning, the reality for many children who have CVI, is that they may use vision to support certain functions and require “blind strategies” for others.<sup>[31]</sup> Using clear and objective ways of measuring and documenting progress in development,<sup>[32,33]</sup> and learning,<sup>[34]</sup> and not just in vision is important in planning further management. Especially children receiving early intervention or who have been given good environmental supports for the very first time may show big changes in visual functioning. It is important to start at the level of the child, but to also recognize that the child may later move in capacity and their intervention plan should reflect this.

## h. Intervention procedures

### 1. Building Visual Awareness & Visual Skill Training

Evidence from studies shows the improvement in child’s level of visual acuity through visual training.<sup>[35-37]</sup> Vision stimulation and visual perceptual learning are the most important intervention strategies which help in improving vision.<sup>[35-39]</sup> The vision stimulation approach is in education and clinical practices for many years to stimulate infants with vision impairment or children with additional disabilities, cognitive challenges, and very rarely react to the visual environment.<sup>[40,41]</sup> The primary focus of the intervention starts with improving the visual functioning.

Visual skill training aims at developing (i) central, steady, maintained (CSM) fixation, (ii) tracking vertical, horizontal, diagonal, and circular movements, (iii) scanning two or more objects presented. It is strongly recommended to be mindful about the dos and don’ts of the training for better impact of intervention. Following are few key points to be kept in mind by the therapist and families while providing visual skill training:

a) Presenting only the lights in a darkroom should be completely avoided at any time b) Therapy should be given only by a trained vision intervention specialist for the entirety of the session c) Begin the training with illuminated objects (e.g., glow ball) in a partially lit room for a brief time to elicit the visual attention from the child. However, this should be reduced gradually with a replacement of non-illuminated brighter objects (e.g., patterned color charts). Upon the improvement seen in child’s response the training materials used can be changed as objects that have direct relevance to the child (e.g., colored eating bowl) with increased visual sphere in the natural illumination as per the child’s visual ability d) The length of the session should be based on the child’s developmental age e) The therapist must ensure the active engagement of the child with what is seen than a passive session f) Vision stimulation materials should be presented systematically and sequentially to motivate the children to see and strengthen their neural pathways and facilitate their vision development.<sup>[40]</sup> g) The extraneous sensory information should be reduced h) The pacing of the stimulus should be slow and steady i) Over stimulation should be avoided to prevent visual fatigue and other health risks j) Flickering lights can induce seizures and hence caution needs to be exercised especially with children who are on seizure medication.

Based on the evidence from the best practices the following material and activities are recommended to improve visual attention and ocular motor functions along with auditory and tactile inputs: a) Illuminated objects, such as glow balls and moving toys b) Non-illuminated bright colored objects: Fluorescent slinkies, pompoms, balls, etc., c) Shiny/glittery flowing patterns/reflecting material d) Colored grids e) Simple patterned high contrast cards f) Strings of translucent beads g) Light box: It has an illuminated surface which makes the transparent/translucent objects (example: colored pinwheels, jelly cubes, transparent colored pegs, etc.) glow and get the visual attention easily h) Mobile and tablet-based third party and open-source vision stimulation applications like Tap-N-See now, Edu Kitty, ABC & 123 Genius, Balloon popper, etc.

### 2. Visual Perceptual Skill training

The illuminated sources can be gradually reduced as the child progresses and three dimensional, two-dimensional objects, and forms can be introduced sequentially. Training in visual perceptual skills like identification, matching, sorting, sequencing, part-whole, spatial relationship, etc., should be introduced as the child progresses with visual discrimination. When the child learns to differentiate two familiar objects through verbal expression, pointing, or eye pointing, the complexity can be increased.

Now assessment of detection and low contrast acuity can be carried out. Visual acuity for near and distance should be done with single symbols than with lines & crowded symbols. Perception/cognitive activities are carried out as per the results from the developmental checklist. Vision specialist and special educator work together in these areas. The results must be shared with parents and other developmental therapists and their opinions should be taken into consideration.

### i. Approaches to early intervention programs

The approach to early intervention service delivery is classified into three kinds. The type of approach that best suits a child should be decided based on factors such as severity of disability, availability of immediate access to services, parental support, economic status of the family, etc. It should be a collective decision of the consulting professional and the family members in selecting the appropriate service delivery model suitable for a particular child.

*Center-based approach:* In this approach, the above-discussed services are delivered in the Vision Rehabilitation Centers which are fully equipped with needed infra-structure and professionals from various disciplines. This approach can benefit children with multiple disabilities as their challenges demand collaborative attention of expert’s services and advanced therapeutic equipment, which may not be feasible to provide in home environment. Additionally, in this approach parents will have the opportunity to interact with other parents with similar children and benefit from parent-to-parent support. Some centers may also provide or integrate educational activities into their sessions. It is important to ensure children have other ways of accessing normal social experiences in addition to such special services.

*Community-based approach:* Given a scenario that a vast majority of these children live in the rural areas where the access to services is limited or non-existent, community-based approach is recommended for rural areas and urban slums.

The services are delivered in the community through the field workers who are trained by the professionals. In this approach, basic assessment tools and therapeutic interventions are used and a trained fieldworker plays multiple roles including raising awareness among the larger community on how they may support the child and family.

*Center and Community-based approach:* The combination of receiving services from both center-based and community-based model is good for those children whose requirement demands expert's opinion but they cannot visit rehabilitation centers due to various personal challenges. This approach blends initial assessment by the expert therapists at the center and the interventions are provided in the home environment through a trained field staff under the direction of the therapists. In this technology era, telerehabilitation helps the professionals, supervisors, fieldworkers, and parents to connect with each other in providing effective rehabilitating care to the needy children.<sup>[42]</sup>

Ideally in all approaches, goals and intervention plans should be based on a good understanding of the home and neighborhood environments, the opportunities and barriers present. The training and institutional collaboration details of early intervention services are listed in the RSBK operational guidelines.<sup>[43]</sup> To name a few centers that provide inter-disciplinary early intervention services are LV. Prasad Eye Institute, Hyderabad, Telangana, India and Sankara Nethralaya, Chennai, Tamil Nadu, India.

## Conclusion

There is an urgent need to scale-up early intervention programs in India considering the magnitude of children with vision loss and developmental issues. Delay in providing timely and appropriate intervention can lead to lifetime consequences and profound exclusion from mainstream for children and their families. A comprehensive approach including early identification, assessment, and intervention which involves the support from a range of stakeholders will ensure that the rights and needs of such children and their families.

The overview of services discussed in this paper can be a reference guide for the stakeholders to initiate early intervention programs in their respective setting so as they assist the needy children to achieve their development potential and participate meaningfully in their home, school, and community environments.

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## Conflicts of interest

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