



Looking beyond cataracts: Meeting visual needs of children with additional disabilities

Namita Jacob^{a*}, Deepika Sridhar^b, Sasirega M.^c

^a Chetana Charitable Trust, Chennai, India

^b College of Optometry, University of Houston

^{b&c} SN-ORBIS POLTC Chennai, India

Abstract. The I-Count registry documents the incidence of visual impairment co-occurring with developmental disabilities, including mental retardation and cerebral palsy. 500 children, in age groups birth to 3 years, 3 to 6 years and 6 to 18 years, are covered in this database. Over 65% of children with surveyed were found to have visual impairment. In a smaller sample of 250 children with cerebral palsy, 17 were diagnosed with deafblindness. Optic nerve atrophy (17.6%) and cortical visual impairment (14%) were the most common eye conditions in the sample. The need for early identification, treatment of refractive errors and appropriate visual accommodations in rehabilitation are discussed. The implications of the findings are discussed in the context of professional preparation programs for clinical and rehabilitation workers and we describe efforts currently underway to strengthen services.

Keywords: developmental disability; cerebral palsy; mental retardation; optic nerve atrophy; cortical visual impairment;

1. Introduction

The World Health Organization estimates that without concerted global action, 76 million people could be blind by 2020, although at least 75% of blindness is from treatable or preventable causes. Rising to this challenge, many governments and non-governmental organizations across the world are working towards the prevention and treatment of blindness. There is much to celebrate as the incidence of trachoma and xerophthalmia reduce and the number of corrected cataracts and refractive errors increase as dramatically (Waters, Rehwinkel, & Burnham, 2004). However, with a little more than a decade left to meet our goals, we must ask ourselves if we have done enough to target the most vulnerable populations. By vulnerable, we mean those who are more likely to have a visual impairment and at the same time have significant difficulties in accessing services; for example, those in remote or rural areas, those in poverty and those with disabilities.

In India, there are many examples of programs designed to meet the challenges of serving those in rural areas and those in poverty (see for example, the Aravind Eye Care System). However, we have no policy or plan for effective assessment, intervention and rehabilitation on a large scale for people with disabilities. WHO, in their Country Health System Profile, estimates that four to 14 million people are blind, 3.2 million have hearing impairment, over 16 million have locomotor disabilities including cerebral palsy and 3 percent of India's children are mentally retarded (WHO, 1991).

Developmental disabilities refer to impairments or lifelong limitations in function due to injury or damage to the brain occurring during the developmental period (Accardo et al.1996). Studies around the world have documented a high incidence of visual impairment particularly among those with developmental disabilities such as cerebral palsy and mental retardation. In India, among children with cerebral palsy, the more visible motor and health issues take precedence in intervention and visual issues are often overlooked (Bhatia & Joseph, 2000). Additionally, visual assessment and intervention involve complex procedures and are time consuming. Standard tests of visual functioning are often not appropriate for use and recommended procedures are often too expensive to implement.

Early diagnosis and effective intervention can significantly reduce the incidence and negative developmental impact of visual impairment in this population. Yet few medical or rehabilitation organizations were found to be equipped to meet these needs. Focusing on this population may mean selecting a group that is not likely to yield the dramatic figures that cataract interventions will. However, if we believe in every individual's right to sight, number should not influence our willingness to take up this challenge.

2. I-Count Registry

In Chennai, both clinical and rehabilitation services were poorly prepared to serve individuals with visual impairment and additional disabilities and little systematic information on their group existed. The "I Count"

* Corresponding author: e-mail address: projects@chetana.org.in Chetana Trust, 15 Arunachalam Road, Kotturpuram, Chennai 600085.

registry of visual impairments in Chennai, South India, was begun in 2004 to fill this need by documenting the main social, clinical and functional characteristics of individuals with developmental disabilities.

The I Count covers five rehabilitation organizations in Chennai. All clinical assessments were carried out by the paediatric department of Sankara Nethralaya, a premier institute for ophthalmology in the country. Separate assessments for visual acuity, ocular-motor, and retinal status were carried out by the paediatric optometrist and paediatric ophthalmologist. All functional assessments were carried out in settings familiar to the child by specially trained rehabilitation teachers. They were also responsible for recording family and medical information. The database was maintained by Chetana, a non-governmental organization, which also took responsibility for compiling and sharing information. From this documentation, it was possible to develop strategies to identify, prevent and intervene with this group more effectively.

The three major goals of the registry were to describe visual issues among children with other developmental disabilities, identify lacunae in existing services and use the knowledge base to enhance existing services

3. Visual impairment among children with developmental disabilities

Today the I Count registry covers 500 children (birth through 18 years) with at least one developmental disability. 296 (59%) of the group had a visual impairment as defined by WHO guidelines. In recording their diagnosis, the ophthalmologist is required to indicate the primary and secondary conditions causing the visual impairment. Other visual conditions that are present but do not cause visual impairment are recorded separately.

3.1 Main features of visual conditions in the sample

Most children had more than one neurological diagnosis as confirmed by a paediatrician or neurologist. The consulting neurologist in the project felt that terms like mental retardation, developmental delay and autism were not being used appropriately by all doctors and suggested a larger category “attentional, behavioural or cognitive deficits” be used to reduce error in reporting. The most common diagnosis in the sample is cerebral palsy. Seizure disorder often occurred along with cerebral palsy (N=144). This group had the highest incidence of visual impairment (N=113).

Ocular conditions causing visual impairment were classified as primary and secondary conditions. The most common primary eye condition was optic nerve atrophy (17.6%), followed by cortical visual impairment (14%) and delayed visual maturation (6.6%) (Table 1). Only nine children in the sample had ROP. Visual conditions not causing visual impairment included strabismus (36.4%), nystagmus (28.2%), astigmatism (20.8%) and amblyopia (7.4%). Myopia (9.6%) and hyperopia (9.6%) were also present. The low number of children with amblyopia could be attributed in part to the method by which vision was tested. In many children it was not possible to test visual acuity by letter chart. Therefore, the criteria “two - lines between the eyes” could not be applied to all children. In 5.8% of the sample, it was not possible to arrive at a diagnosis.

Table 1: Most common ocular diagnoses in the sample

Primary diagnosed visual condition	Total number of children	
Optic nerve atrophy	88	(17.6%)
Cortical Visual Impairment	70	(14%)
Delayed Visual Maturation	33	(6.6%)

A large number of the children in the sample had uncorrected refractive errors, astigmatism, and strabismus. We asked a subset of children (178 children) at what age they got their diagnosis, to see if some conditions were being missed more than others. Visible conditions like albinism and anophthalmia were identified by 6 months. 90% of the children with CVI were identified before the first year. However, more than 40% of refractive errors, strabismus, cataracts and optic atrophy were identified after the first year (see Table 2)

Table 2: Age of children when diagnosed with the visual condition (N=178)

Diagnosed visual condition	Age at diagnosis		
	Less than 1 year	1 - 3 years	> 3 years
Cortical visual Impairment	90%	17%	3%
Optic nerve atrophy	68%	8%	14%
Cataracts	60%	20%	20%
Refractive errors	57%	25%	18%
Strabismus	50%	20%	30%
Amblyopia	23%	16%	61%

Inconsistent visual performance (20.8%), eccentric viewing (15%) and eye pressing (4.8%) were common behaviours noted among children in the sample. Delayed response (more than 3 seconds before any orientation toward the stimuli) was added as a new category after it was documented in 64 children.

4. Lacunae in existing services

The registry began with three rehabilitation organizations serving children with cerebral palsy and mental retardation. The initial focus was to assess the youngest children and those identified by teachers as having a vision concern. When the registry reached 250 children, the first analysis of the data was done.

4.1 Lacunae in clinical services

A large number of children had visual impairment (165 of 250 children). In spite of the accessibility to ophthalmic services in the city, in each centre, 24-27% of children were prescribed spectacle correction for refractive errors for the first time. As seen in Table 2, there is delay in identification and therefore basic intervention for many children with refractive errors.

For many children, visual acuity measures were hard to obtain and visual acuity was being recorded in different ways, making it difficult to compile and analyse the data. There was no protocol for recording visual acuity when a child is unable to read a chart. As many clinicians were not used to assessing children with disabilities, they found it difficult to interpret functional behaviours unique to this group.

The clinical setting itself presents challenges to the process of assessment. Children are stressed by the strangeness of the place, the crowds and the cool air-conditioned temperature can cause increased muscle tone.

4.2 Lacunae in rehabilitation services

Although in most cases, it was the teachers who first identified the child having trouble seeing, simple interventions such as distance, size or contrast had not been implemented for approximately half of the visually impaired children. Visual impairment is discussed in the curriculum for the teacher of children with cerebral palsy and mental retardation. However, we found that it covered learning needs of children who have only visual impairment and their common eye conditions such as xerophthalmia and corneal defects, instead of those things relevant to visual impairment associated with cerebral palsy.

4.2.1 Deafblindness in the sample

21 of the 250 children surveyed had a diagnosis of hearing impairment in addition to cerebral palsy. 17 of these children were found to have visual impairment. Children with deafblindness and cerebral palsy form a unique, complex, and challenging group to serve, requiring teachers specially trained to intervene appropriately. This surprising finding of many children with cerebral palsy and deafblindness led us to conduct the I-Count in a school serving deaf children with additional disabilities. We found 9 children who were deafblind.

The institutes providing rehabilitation services for cerebral palsy were serving more children with deafblindness than the center that specialized in deafblind services! Yet, none of the teachers were qualified in this area; indeed, there was little awareness in the centers about the special programming needed for these children. For example, of the 250 children in the sample, only 12 had complete hearing examinations. Two children had hearing aids and just one child used it.

5. Enhancing service quality

It was apparent that early identification and early referrals for visual assessment and intervention had to be strengthened. We had to work toward better teaming between clinical and rehabilitation services. There had to be sharing of existing knowledge and strategies, and most importantly, the professional preparation curriculum had to better reflect the reality of the children who needed services.

The first outcome of the registry began with the simple act of counting. The organizations involved in the I-Count became quickly aware of the lacunae long before the data was compiled and had already begun to examine practice and take active steps to improve their services and the knowledge of their staff. Today, four years into the registry, services in Chennai look extremely different.

5.1 Improvement in procedures for assessment and service delivery

An entire day has been set aside by the paediatric ophthalmologist for individuals with additional disabilities, allowing for greater flexibility managing the patient flow, and helping the ophthalmologist to work around each individual's state of readiness and particular needs. The hospital and rehabilitation organizations are also trying to set up a system for assessment within the schools as a standard practice.

Children go for clinical evaluation after at least one functional review is completed. The I-Count form goes with the child, so the doctor has a ready reference to rehabilitation findings. The child and parent are prepared for the clinical examination and are therefore better able to participate in the process. Parents are advised to carry extra clothes to keep warm in the hospital. They carry favourite toys to help calm the child and elicit more natural participation in the assessment process. Teachers often send notes to the doctor with their observations or questions. The doctor's report includes specific suggestions to support visual functioning. Compliance with glasses and occlusion therapy has improved as the rehabilitation staff coordinates with the ophthalmologist.

An analysis of recommendations for accommodations made by the rehabilitation staff in 2004 and in 2006 after the enhanced training shows a substantial increase in the use of strategies like pacing (1 recommendation in 2004 to 40 in 2006), position of child and object (25 to 41), and contrast (39 to 52) that better reflect the visual conditions (ONA and CVI) that are present in the group. In 2004, the standard suggestion was to increase contrast and size and reduce distance.

5.2 Improvement in professional preparation

The increased number of children with developmental disabilities visiting the paediatric department created interest in the special challenges they presented. Ophthalmology Fellows placed in the paediatric department automatically had good exposure to this group of children. As they move out to other hospitals, we have had requests for training and support from other parts of the country. Optometry students now have significant exposure to principles of assessment and intervention of children with additional disabilities in their theory, practical placement and final evaluation in the third year of their four year basic degree program. An M Phil project was based on questions that arose from working with this group. Continuing Medical Education (CME) courses for ophthalmologists included a focus on children with developmental disabilities.

The teacher preparation programs in the centres for cerebral palsy and for deafblindness enriched their curriculum to include a specific focus on understanding and accommodating visual issues. This year, the first Continuing Rehabilitation Education (CRE) short course that summarizes the lessons learnt will be opened to the rehabilitation community. In its second edition, the first Indian text book for visual impairment and additional disabilities will include information on children with cerebral palsy and visual impairment and discusses the impact of the combined impairment of vision and touch on learning and development.

5.3 Improvement in levels of awareness

Initially, the majority of the children who came to the five organizations were referred from hospitals and clinics for what was seen as their primary disability – cerebral palsy, mental retardation or hearing impairment. Today, referrals to the same organizations come specifying the need for visual rehabilitation, pointing to the raised awareness of the larger medical community. On an average, three new children with visual impairment and additional disabilities are seen every week in the two major centres for children with cerebral palsy. The increase in referrals from community members has also been very heartening.

6. Conclusion

We need to develop protocols for assessment of children with developmental disabilities that are viable within the financial, time and manpower restrictions of the developing world, where the majority of these children live. We should re-examine the definitions of visual impairment within the context of this group, where an impairment of the visual system can have a dramatic impact because of the existence of another impairment of functioning – such as movement, haptic exploration or hearing. The extent and nature of visual needs must be assessed in order to plan for appropriate training and services.

There is an urgent need to develop professional capacity to assess vision, and develop interventions meaningfully for children with developmental disabilities. They represent a significant percentage of the population of children who have visual impairments. At least in Chennai, we have seen that without a focused effort, their visual needs are being overlooked. As a world community that believes in the Right to Sight, we cannot continue to overlook this group of individuals.

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