

**Title: Counting on sight: visual impairments among children with developmental disabilities**

**Focus:** *Achieving Quality in Education: Strategies for Change*

**Topic:** *Multiple disabilities & visual impairment*

Abstract: This presentation describes the rationale behind establishing the first registry of visual conditions among children with developmental disabilities in India. Although visual impairments are known to occur at higher rates among children with developmental disabilities, it still receives inadequate attention both in identification and in rehabilitation in India. Good service delivery requires an understanding of the impairments involved as well as the social and educational features of the population that needs services. The I-Count was therefore designed as a comprehensive registry, including information on the child's family, health and functioning, as well as the services received. This allows for easy identification of gaps in services and knowledge and offers immediate guidelines for preparation of professionals working with this population.

The results have been applied to enable specific programming for the children surveyed; to create training programs for parents, medical professionals and teachers; and to redesign the module for special education teacher preparation courses. We propose establishing a national registry of data collection to enable data collection over larger populations to better understand the needs of children with multiple impairments. This project asserts that every child counts, that vision plays a vital role in learning for all children, and access to appropriate vision services is the right of every child.

## ***Counting on sight: visual impairments among children with developmental disabilities***

Chetana is a non-profit organization with the goal of making learning accessible to all. The notion of *access to learning* goes beyond simply ensuring formal education, as it implies providing people with the opportunity and tools with which to actively seek and discover. Thus, our projects aim to make information easily available so that people are both motivated and able to access it.

I-Count is one such project where we have created a documentation format to catalogue the visual conditions prevalent among children with developmental disabilities. 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). Although visual impairments among children with developmental disabilities are well documented in medical and rehabilitation literature, it still receives inadequate attention both in identification and in rehabilitation around the world (see for example, Bhatia & Joseph, 2003; Flanagan et al, 2003; Hatton, 2001).

Appropriate services to individuals with multiple disabilities require a good understanding of the ecological context of development and growth. I-Count was therefore designed as a comprehensive registry, including information on the child's family, health and functioning, as well as the services they receive. This allows for easy identification of gaps in service delivery and knowledge and offers immediate guidelines for training or preparation of professionals working with children with developmental disabilities.

### **The creation of I-Count: Establishing a registry**

The effects of visual impairment on learning and development when the child also has an impairment in another area of functioning can be devastating. For children with motoric delays such as cerebral palsy, the access to the larger world that they cannot physically reach and explore is largely through their eyes. For children with mental retardation,

where language processing is often a challenge, visual feedback gives them an important additional way to make sense of the world. Visual conditions themselves are complex, and the implications for learning and development vary depending on the cause of impairment, its location, severity, the time of impairment and what other conditions occur along with it. Good rehabilitation and medical decisions must be built around an understanding of such issues.

Many studies, largely from the economically developed countries, have documented that sensory impairments, particularly visual impairment, occur more frequently among children with developmental disabilities than in the general population (for example, Guzetta et al, 2001; Nordmark, Hagglund & Lagergren, 2001) This is not surprising, since many of the underlying causes of brain damage and injury such as prematurity and birth asphyxia, are known to affect the visual system as well (Dowdeswell et al, 1995). This is important as the clinical spectrum of developmental disabilities like cerebral palsy have been found to be different in developing countries pointing to the danger in assuming similarity in the features of co-occurring visual conditions as well (see for example, Singhi, Ray & Suri, 2002). While many studies in India and the developing world document disability data, few examine the co-occurrence of disabilities, the few that do are based on small samples in very different economic and geographic areas of the country (see Bhatia & Joseph, 2000 and Srivastava et al, 1993 for example).

Bhatia & Joseph (2000) reporting on 100 children with cerebral palsy found that 82% of the children had co-occurring conditions apart from locomotor disabilities. Although 43% of the patients had been referred by a primary care physician, one or more associated disabilities had not been recognized and epilepsy was the only associated condition that had been treated prior to the evaluation. They call for greater awareness in the medical and rehabilitation community on the nature of impairments associated with these children and the importance of intervention dealing with all areas of need. However, currently available guidelines for intervention, medical investigation, categorization of impairment and areas of focus in rehabilitation are drawn from available statistics based on data from the economically developed countries. These are unlikely to reflect the status of children in India or low-income countries, where the etiology and health profiles of developmental

disabilities are not the same as in wealthier countries. The result is inadequate medical care and educational programming that impacts lives as seriously as a primary disability.

Good data allows us to plan responsive services and to answer questions about diverse issues such as the value of intervention, the gaps in services and the impact of various interventions. Although we bemoan the lack of such information, the pressing need to provide services to the vast numbers of children and families, takes precedence in most service organizations. Chetana's aim was to create a database that served a dual purpose. The first was to encourage the complete evaluation of vision – clinical and functional - among children with additional disabilities; something we had realized was not happening adequately. The second was to utilize information typically available and organize it in such a way that it would yield useful information to professionals. Through I-Count, we assert that every child counts. By documenting locally prevalent issues among this population, we believe we can facilitate system level change by making this knowledge available to professionals and families.

## **Data summary and reporting**

The I-Count form gathers information on the child's family, medical issues, sensory status and services. The ophthalmologist fills out the medical assessment while the rehabilitation professional fills out the remainder of the form based on her observations, medical reports and conversations with the parents. A pediatric ophthalmologist from Sankara Netralaya eye hospital provided us with support for the visual assessment of the majority of the children. The I-Count project began with two organizations in Chennai. A separate I-Count form was maintained for each child and given a unique identification number to ensure the records remain confidential. The completed forms were entered into a master database. Over a period of two years, 232 students from these organizations had completed and entered forms.

Used over time and over larger populations, I-Count can become a source of data that can support research questions on etiology, visual conditions, prognosis, incidence, and other such issues. Already the World Bank has used information from this database in their work that attempts to describe and quantify issues related to disability in India. The

format is designed so that much of the information gathered is directly comparable to information being collected in Canada and the United States of America. There is interest in utilizing this format in other parts of the world, and this would add immensely to the richness of information that can be culled from this database. Particularly relevant to personnel preparation, is the understanding of patterns of occurrence of visual issues and associated conditions in different parts of the world.

However, a major goal of I-Count was to have an immediate impact on services by enabling different professionals to quickly access information that would alert them to any lacunae in their services and to provide information that would help them in planning services. The data is organized so that the viewer can request reports summarizing basic information on family characteristics, child health and impairment characteristics and visual conditions and interventions. The information generated was specific to the children and families surveyed and not meant to be generalized to the larger population at this point. However, in meeting the needs of these children, we believe we have ensured an improved quality of services for a greater number of children just by raising awareness among professionals of issues in current services.

### **Help plan support for parents**

For many parents, this was the first time that attention of both rehabilitation and medical professionals was on the child's visual capacity. Apart from personal counseling sessions, it seemed helpful to create materials on issues relevant to visual impairments in children with additional disabilities which could be handed to parents. The information materials were designed keeping in mind the literacy status of parents, shown in Table 1.

**Table 1: Levels of maternal education in the sample**

Maternal education	Total surveyed	Children with vi
None	26	14
Primary	18	12
Secondary	51	37
11 <sup>th</sup> & 12 <sup>th</sup>	72	42
educated beyond school	57	42
no information	8	6

We found that the majority of the mothers were likely to be literate and comfortable with reading. However, there were several mothers with no education or only primary education and we felt the material should meet their needs as well. We prepared simple materials in English and Tamil, limited the information to a single page and illustrated the main ideas (available for free downloading on the Chetana web-site; <http://www.chetana.org.in>).

### **Help plan support for students**

Of the 232 children surveyed, 153 had visual impairments in addition to other impairments. Many children had a combination of visual conditions as secondary conditions, reported in Table 2. Since each eye can have different diagnoses, we report the number of eyes affected rather than the number of children. The five most common causes of visual impairments among this group were optic nerve atrophy, cortical visual impairment, delayed visual maturation, congenital cataracts and myopia. These conditions most frequently occurred along with cognitive disorders, cerebral palsy and seizure disorders.

We observed that for more than 50% of the children with diagnosed visual impairments, teachers reported that no environmental modifications (such as lighting conditions, higher contrast and so on) were being used. In response to this, apart from in-service training for teachers and community based rehabilitation workers, we worked to reshape the teacher preparation curriculum to better reflect the needs of the children actually being served in the schools. Two short courses – a four day program focusing on “Issues in visual assessment and intervention for children with visual impairments and additional disabilities”, and a ten day training “Intervention for children with multiple sensory impairments” were developed. It is now part of the course curriculum for the teacher preparation program. The courses focus on the visual conditions identified through the survey and highlight intervention needs specific to common combinations of impairment we see in the database.

**Table 2: Nature of visual impairments among children included in the survey**

Visual Condition	# Primary	# Secondary
Albinism	-	1
Aphakia	2	-
Cataracts	2	12
Chorioretinitis	-	1
Coloboma	1	3
Congenital Ocular Motor Nystagmus	2	2
Corneal Defects	-	4
Cortical Visual Impairment	12	55
Delayed Visual Maturation	4	32
Hyperopia	12	-
Leber's Anomaly	4	-
Microphthalmia	2	2
Myopia	-	45
Optic Nerve Atrophy	113	8
Optic Nerve Hypoplasia	3	-
Retinopathy of Prematurity	4	-
Unknown (tested, but not yet diagnosed)	17	-
Others	15	17

## **I-Count as a way of improving services**

Being obliged to enter information in every question in the I Count format, helped highlight problems in assessment and documentation for each of the professionals involved. The commonly used definition of visual impairment requires the documentation of visual acuity and visual field – neither of which are easily obtainable in the majority of the children in the database. When acuity could not be measured using charts, alternate terms such as the ability to fix on a visual target and the ability to follow it, is advised. In practice, this method was found inadequate for the children surveyed and we developed a system of documentation that enabled consistent information to be gathered across all the children surveyed. This system has become part of the training program for Optometrists at the Elite School of Optometry, Sankara Netralaya, and the third year students do part of their clinical experience under faculty supervision, supporting Chetana as we continue to work with different organizations in Chennai. We

hope that future optometrists from this institution, feel comfortable and competent in carrying out assessments for children with additional impairments.

## **Conclusion**

Through I-Count we have demonstrated how simple documentation when managed well can improve services at all levels – prevention, identification, assessment and intervention. Apart from skill and knowledge levels of professionals involved in the trainings, the awareness levels in general have changed. Teachers, parents and professionals such as therapists, pediatricians and others who interact with the child, are quick to notice and refer for visual issues. The result is earlier access to appropriate services. We hope to engage with organizations to take this effort further, allowing us to create a registry so that our practice is always responsive to the reality of the children we serve.

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