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How to assess and plan for the management of visually challenged children in the context of multiple "different-abilities"

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Is my child seeing? Does she have any vision? Does she comprehend when we speak to her? These are common questions from perturbed parents. But most of the time they are sure that such children have some vision. 15-month-old Jyothika* was referred for vision stimulation by her physiotherapist. Jyothika sustained cerebral palsy after severe seizures three days after she was born. Her vision was stimulated and reinforced through her other senses and cognitive abilities. Simultaneously the other developmental domains – speech and language, ocular motor, and sensory-motor integration were worked on to attain optimal visual perceptual abilities for her age. Providing visual materials consistent with visual potential, seizing and reinforcing all visual attempts, and making the environment visually stimulating all contribute to maximizing the visual potential in such cases.

Vision brings an enormous amount of information just at one glance. Nearly 80% of information about the world is assimilated through vision. Learning is mediated through vision. It is a central integrator of input from other sensory channels. Vision is primary to motor milestones as well as to the other aspects of developmental tasks.

Children without vision rely on other senses – hearing and tactual-kinaesthetic – to perceive the world. But for children with multiple challenges including visual, difficulties with hearing or motor

development, sensory-motor integration, language development, learning disabilities, and problem solving make the development of perceptual abilities more challenging. Assessment of such children too then poses a challenge.

Principles behind the assessment process:

Parents/care-givers as information providers and the decision makers:

Parents/care-givers are more knowledgeable in providing information about the child's capabilities. They have more opportunities to observe the child in varied settings. Simple and specific questions to the parents/care-givers can contribute to the test results and the subsequent planning of intervention. Their involvement in the assessment process also helps in identifying and deciphering the child's responses. Parental involvement can facilitate a working relationship with the professionals that promotes acceptance and compliance to the interventions.

Duration of assessment: A child's activity level determines the duration of the assessment. Information about the child's capacities cannot be gathered in one session of assessment. The assessment has to be carried out in varied settings and the test results need to be verified with interviews with the parents or the care takers. Hence to add to the credibility of the test results two or more sessions has to be planned.

Assessment should begin as soon as the evaluator has the opportunity to observe the child: Careful observation of the child will be additional information to the assessment result.

Areas of assessment

Prior to assessment, medical and general information should be gathered. Consent for this has to be obtained. This information will form a basis for planning interventions and also provides an overall picture of the child's functioning.

Ophthalmic diagnosis and optometric evaluation are important to gain an understanding of the visual potential, nature of loss and the visual prognosis. These essentially determine the functional implications of the disorder and help in choice of assessment and the training materials.

Additional medical information on the other health concerns such as seizures, hearing impairment and the like are valuable in the assessment process. Information on intake of any drugs/medicines is also useful so as to determine the side effects and its influence over child's behaviour particularly the level of alertness.

Functional vision assessment:

The score in the objective evaluation of vision may not actually depict the visual performance of the child. The degree of problem in the child may also deter the determination of the objective results. The

child has to be subjected to simple and result yielding testing procedures to establish the level of visual and visual perceptual abilities. The outcomes decide on the need for vision stimulation in younger children (particularly for cortical blindness) and the type of training materials, assistive devices and the learning medium for the older children.

Determining the developmental quotient: The chronological age determines the range of developmental activities the child has to possess. Motor, self-help, language, social and emotional development form the baseline for the interventions. Insight into the child's cognitive skills and perceptual attributes enable one to construct assessment procedures, plan interventions accordingly and to identify the ability of the child to generalize the skills attained developed in the course of intervention.

Special Considerations in the assessment procedures

Versatility of the evaluator: The evaluator should have a strong working knowledge of the assessment tool and various procedures. This means that the evaluator is not dependent on constantly referring back to the protocol for the next step.

Type of materials: Materials should be age appropriate, visually appealing, and

simple enough to provide tangible results. Considering the attention span and the other physical problems of the child, choice should be in such a way that many attributes could be assessed with one particular material. Also principles in presentation of the material should be considered based on the nature of problem. The materials could be complex, brightly coloured if the child suffers just an ocular impairment. Visual clutter has to be reduced in case of cortical blindness.

Establishing rapport: The evaluator should be capable of eliciting and sustaining the child's response. The entire evaluation must be carried through active play as this enables better interaction. However, the child's parents or other familiar persons can be present to make the child feel comfortable.

Responses of the child: The responses of a child with multiple challenges may not be explicit. The evaluator should be alert enough to pick up even subtle signals like change in respiration, muscle tone, vocalizations, quieting, slightly increased bodily movements or stilling. It is important to gather information on how the child uses the senses to interact with the object present. Vision may or may not be always the dominant sense. The child may

explore tactually, hear the sound of the object before actually directing the vision on it. This provides an insight into the child's learning pattern as well.

As with all children, this population of special children deserves careful attention so that optimal assessment results may occur. Common concomitant disabilities include hearing loss, physical disability, and developmental challenges.

Bibliography

Alan J. Koenig, A. L. (1996). *Foundations of Low Vision: Clinical and Functional Perspectives*. AFB Press.

Anthony, T. L. (n.d.). *FUNCTIONAL VISION ASSESSMENT FOR CHILDREN WHO ARE YOUNG AND/OR MULTI-DISABLED*. Retrieved August 15, 2007, from The Teaching Research Institute: http://www.tr.wou.edu/ntac/documents/conference/2004_topical_workshop/Partial-FVA-document.pdf

Lueck, A. H. (2004). *Functional Vision: A Practitioner's Guide to Evaluation and Intervention*. AFB Press.

Sandy Niemann, N. J. (2000). *Helping Children Who Are Blind: Family and Community Support for Children with Vision Problems*. Hesperian Foundation.

Wachs, T. D., & Sheehan, R. (1988). *Assessment of Young Developmentally Disabled Children*. Springer.

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A community ophthalmology program and hospital transformation in Central India

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Background

Sadguru Netra Chikatsalaya (SNC), a 350-bedded eye hospital situated in Chitrakoot, Madhya Pradesh, serves a population of approximately 25 million. There are few government hospitals and private practitioners in the area, and SNC is the only place offering speciality eye care services.

In the past, SNC had been providing cataract surgery, inserting intra-ocular lenses in only 25% of cases. Nevertheless, it remained popular with patients because of the 'compassionate care' provided, with food, clothing and safe stay at the institute.

SNC lacked a formal cost recovery strategy. It provided free service to the poor, and sought donations from those

that were willing and able to pay, as well as donations from disciples of the founder. As a result it only managed around 50% cost recovery.

The SNC philosophy included a strong sense of community service, but no active mechanism to provide service to the community. In particular, SNC lacked the professional management to develop community ophthalmology strategies and programmes. SNC had a seasonality problem also.

Prior to 2001, SNC faced several challenges addressing all facets of

management from erratic demand, seasonality, quality, institutionalized camp approach, human resource management & financial sustainability



A gradual shift in philosophy occurred in 2001 without diluting the core objectives of community service. In this process, the Director of SNC played an important role in convincing the trustees of the need for change. The top management agreed to adopt modern management practices and to seek outside help to address hospital and community needs.

In 2002, SNC underwent an extensive evaluation with the help of the ORBIS International, a global non-governmental organization, Seva Foundation, a US non-governmental organization and the Aravind Eye Care System from Madurai, Southern India.

The team from ORBIS, SEVA and Aravind found issues related to availability, affordability, quality of services, speciality care, technological advancement and a large unmet need for eye care in the areas SNC could serve.¹

The evaluation team concluded that, without significant internal restructuring and extensive efforts to build external relations, this hospital would find it difficult to sustain services, manage the huge flow of patients and overcome a looming financial problem due to reduced support from the Mafatlal Group of Industries, the principal supporter of SNC and other donors.

The SNC team (comprising its trustees) visited Aravind Eye Hospital and participated in the Vision Building Workshop at LAICO in 2002. A panel of experts from Aravind, ORBIS and SEVA suggested changes to management, human resources, financial structure and the establishment of a dedicated Community Ophthalmology Department. This paper reports the changes over the past 4 years at SNC.

Interventions

Training

Two SNC staff received training at Aravind Eye Hospital in "Community Outreach and Social Marketing of eye care services" funded by SEVA and ORBIS. As a follow up, the Camp Manager from Aravind visited SNC to demonstrate how to organize outreach camps with the support of the community. A project manager was appointed and later trained in eye care program management at the All India Institute of Medical Sciences (AIIMS), New Delhi.

Ophthalmologist skill development began in 2003, initiated by ORBIS. The hospital-based training by international and then

local experts improved cataract surgical skill at intra-ocular lens insertion. Clinical protocols were established and routine medical audits were begun. For pediatric ophthalmology, medical professional volunteers from ORBIS trained SNC ophthalmologists on cataract and strabismus surgery. These programs were publicized widely. Once the demand increased an experienced pediatric ophthalmologist was appointed. Another ophthalmologist was sent to the LV Prasad Eye Institute in Hyderabad for long-term Pediatric Ophthalmology Fellowship program. SNC sponsored candidates for the international short-term fellowships in Pediatric Ophthalmology and Occuloplasty in the United Kingdom. The fellowship program in Occuloplasty significantly strengthened the pediatric ophthalmology department.

Community Programs

The community ophthalmology program began in May 2002 with cataract and refractive error outreach camps in underserved areas where people already knew about SNC. A familiar population helped increase attendance at the outreach camps and as the SNC team grew, outreach camps were organized in new venues with the support of sponsors.

At the outreach camps, an ophthalmologist examined patients. Refractive errors were treated with spectacles at subsidized cost or free for those too poor to pay. Patients with minor conditions such as conjunctivitis were given topical medications. Patients with cataract were transported to SNC for surgery. Surgery was either performed free or payment according to ability to pay. After 45 days, follow-up outreach camps were conducted in the same area to provide spectacles for cataract surgical patients.

The outreach camps directly targeted poorer communities and older women in remote and underserved areas using available hospital staff.

Child community eye programs started later, in October 2002, with support of ORBIS. Qualitative research (FGD) was conducted in December 2002 to find barriers to pediatric eye care services in the project area.² SNC began a school eye screening program, child outreach camps and health education sessions in Satna District, Madhya Pradesh. Schoolteachers were trained for this and for referral services.

Ophthalmic assistants from SNC examined children referred by teachers,

and provided medicines in these camps. Children with refractive errors were given spectacles and those who require further clinical management (surgery / diagnosis) were referred to SNC.

Financial Structure

A three-tier system of pricing was introduced whereby poor people received free services, middle-income group subsidized services and higher income people paid for services.

Results

From 2001 to 2005, the total hospital surgical rate doubled from 23,000 to 45,000 cases. Before 2003, 43% of the total surgeries were performed on women of all ages, which increased to 48% by 2005. There was an increasing trend in the percentage of people over age 50 years accessing surgical services during this time span. During the same time period, seasonal variation in surgery reduced dramatically. From 340 (12%) surgeries between April – September, 2001 the surgical volume increased to 5000 (40%) in 2005.

Publicity campaigns and recommendations from patients with successful surgery had an effect on the direct (walk-in) patients to the hospital during the slow summer months as well. This reflected in the rise of the number of patients who accessed eye care services by visiting the hospital directly, increasing from 10 to 49% between 2001 and 2004. Due to better reach out of services the proportion of females (Table) visiting the hospital increased after intervention.

Childhood ophthalmology

The child outreach program has screened over 200,000 children in the states of Madhya Pradesh and Uttar Pradesh, working primarily through schools. In 2005, in addition to the schools, activities at the community level started targeting non-school children and school dropouts. The demand for services brought out by intervention of community eye program led to the establishment of Children's Eye Care Centre in the year 2004. Before any community intervention only 173 surgeries were performed in the hospital, which has increased to 878 surgeries after intervention (Table).

Primary eye care facilities

To improve access to and the quality of eye care services, "vision centers" were established in 4 areas.

The vision centres have screened 7393 patients, distributed 2022 spectacles and referred 1116 patients to SNC for further treatment and management.

Table: Age and sex comparison of surgery patients at SNC

Age-group	2002-2003		2003-2004		2004-2005		2005-2006	
	M	F	M	F	M	F	M	F
<18	270	167	440	239	447	229	548	328
18-50	1586	1882	2444	3521	1992	2428	2522	3389
50-60	2802	3790	4788	7482	3539	5235	4306	5446
60+	10616	8201	12215	7083	17343	17263	16950	13558
Total	15274	14040	19887	18325	23321	25155	24326	22721

Financial recovery

In the year 2001-02, SNC's paying patients were less than 1%. This increased to 12% in 2005-06. The hospital recovered 100% of its operational costs in the year 2004-05. Approximately 90% of the services were provided at no / affordable cost to the patients, with the rest as subsidized and full paying categories. SNC also continued to receive support for non-recurring expenses from its volunteer donors and partners.

Human resource development

Human resources changed from about 80 staff in summer months and another 70-80 temporary staff added in the winter (2000-01) to about 220 permanent staff in 2004-05 with less than 25 temporary staff added in the winter months. The 200-outreach camps conducted in summer months, utilized most of the additional available hospital human resources. Virtually all of the ophthalmologists and paramedical staff had work throughout the year.

Leadership at the top management level, especially the Director, played a key role in initiating and sustaining the changes in SNC. SNC also developed and retained second level leadership in various specialty departments and the community ophthalmology program.

Discussion

A systematic, well-planned and focused community ophthalmology program reduced seasonal imbalances, improved utilization of human resources, and cost recovery helped lead to the financial viability of SNC.³ Outreach camps benefited the otherwise unreachable poor who had limited access⁴ to eye care services.⁵

The introduction of IOL surgeries not only helped to retain more ophthalmologists

but also attracted more paying patients to utilize SNC. More recent and more advanced surgical techniques, such as small incision cataract surgery and 'Phaco-emulsification' surgery drew more ophthalmologists to the hospital. These ophthalmologists were then promoted for speciality work in glaucoma, pediatrics and Occuloplasty.

The partnership with ORBIS helped SNC to implement community interventions benefiting children of all ages and setup a Children Eye Care Centre (CECC).

Community interventions and vision centres brought SNC's thinking in line with the Government of India VISION 2020 Plan of Action. SNC has plans to open 40 such centres by the year 2020. The centres were able to recover 65-70% of operating costs in the first year of establishment and project cost recovery within 3 years by providing Primary Eye Care Services & referral.

SNC has shifted from passively providing services to the people, who come to the hospital 'directly' to an active approach, based on valid scientific assessment of population health needs. Research studies have been implemented to understand barriers to eye care service utilization and are planned to test community models for interventions.

Sustainability and self-sustenance⁶ of services revolves around optimally functioning of eye care systems.⁷ In the hospital this involves an effective professional management system and an economic self-sustainability model. For the community ophthalmology program, optimal utilization of available resources⁸ required a change in the mindset of patients and hospital management to actively provide comprehensive eye care and education in relation to community needs.

Conclusion

We conclude that community ophthalmology programmes are one of the few active strategies available to a hospital to shape its population health impact. In the SNC example, the community strategy resulted in a steady workload of the hospital, which helped to attract and retain more professionals, regardless of the rural location. The lessons from this community ophthalmology experience can be extrapolated to other hospitals in Central and North India facing similar challenges.

References

1. <http://www.censusindia.net/data/chapter5.pdf> [2001].
2. B K Jain, K Anand Sudhan, Sangeeta Pinto, Strategies to involve community in addressing the challenges of Childhood Blindness, Community Eye Health Journal Vol 18 No.56 2005 pps69-s70
3. Vinod K Sahney. Managing Variability in demand: a strategy for productivity improvement in health care services, Health Care Management Review, P37-41, 1982.
4. Martin H Spencer. Cataract Surgery in Developing Countries: Bridging the Technology Gap, Operative Techniques in Cataract and Refractive Surgery 3, p156-160, 2000.
5. Astrid E Fletcher, Martine Donoghue et al. Low uptake of Eye Care Services in Rural India, Archives of Ophthalmology 117, p1393-1399, 1999.
6. Rao GN. Self sustainability in eye care. Indian J Ophthalmol 1996;44:129-129.
7. B R Shamanna, Rakhi Dandona, Lalit Dandona, Gullapalli N Rao. Financial Sustainability. Comm Eye Health 2001;14(37): 7-8
8. Gina S Krishnan, The Vision of Dr. V Business World. July 5, 2004. Available from: www.google.com [15 February 2007].