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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.

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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

