Best resource use for disabled children

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In Bangladesh the prevalence of disability in a population of children aged 2–9 years from both urban and rural areas was estimated to be 70 per 1000 for all grades of severity and 22 per 1000 for serious disability. The vast majority of disabled children in the country remain unrecognized. Childhood disabilities are responsible for a substantial drain on economic resources in households and for enormous stress in families and the affected children themselves.

Clearly, where no services are available it is necessary to seek community-based, low-cost solutions. A two-stage method of identifying childhood disabilities in large communities has been well evaluated and replicated, and programmes have been established for the home-based rehabilitation of children living far from services.

Screening for disability

A screening method should be applicable to all the children in a community. It should be simple, rapid, and usable by persons who are not highly trained. Two large-scale methods have proved ineffective: the population census and the “key informant” approach, whereby a village elder or schoolteacher is asked to name all disabled children in a village. Both methods underestimate disabilities, especially in younger children and girls, and in respect of cases of impaired vision and hearing which are not very obvious.

The administration of a ten-point questionnaire to all mothers of children aged 2–9 years in door-to-door surveys has, on the other hand, proved useful in finding children with epilepsy and disabilities of motor activity, vision, hearing and cognition. The effectiveness and accuracy of this method were studied in 10299 urban and rural children in Bangladesh and other developing countries (1,2). It was found to be of value for the following reasons.

- It covers every household in a given area, promotes equity and builds goodwill towards service providers.
- It helps to identify the children most in need of help, on average 10–15 per 100 screened.
- The recording of household characteristics during the surveys can help to identify social and economic factors related to disabilities.

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Developmental assessment

Screening would be futile if it were not followed by further evaluation of children found to have disabilities. The underlying biological processes or impairment causing disability may be complex (3). Whereas a disabled child needs help in order to be functional in daily life, the impairment may be part of a disease process requiring medical management and short-term treatment. Thus if a child is severely undernourished, or suffering from night blindness caused by vitamin A deficiency, or from epilepsy or ear infection, it is pointless for the mother to be taught to provide stimulation or play activities for improving cognitive development unless the acute problem is treated. Both impairment and disability require assessment by a child health physician and, in the interest of appraising cognitive functions and intellectual abilities, by a psychologist if possible.

In Bangladesh the success of screening programmes has depended on the effectiveness of developmental assessment, which may be conducted at a central point in a village and produces the best possible yield when done within few days of screening. It is effective in the long run for the following reasons.

- Disability status and underlying impairment are recorded for each child.
- A child may have more than one disability caused by a single biological condition, and this requires recognition. Functional problems in such a child are often much more complex than in one with a single disability.
- Problems that require immediate attention are identified and treated.
- Information from screening and assessment can be combined in order to gain indications as to how rehabilitation should proceed.
- Risk factors or probable causes of disability can be identified, and this may provide important indications for prevention.

Community workers can play a part in developmental assessment

In order to spread services as widely as possible it is necessary to consider whether lay people can be trained to do developmental assessments and accurately identify at least some disabilities in children. Observations on children performing a set of activities can often reveal more than formal neurological testing does about underlying impairments and disabilities. When community workers who had passed eighth grade were asked to identify specific problems in accordance with a previously described method (4) the following results were obtained:

- some problems, especially serious motor and speech disabilities, were consistently and reliably identified;
- most other problems were consistently overlooked.

The explanation for these somewhat disappointing results may be that the procedures were deceptively simple. The observation and evaluation of a child’s activities require a larger experience and
knowledge of child development than the community workers had. It is unreasonable to assume that a week's training can enable a community worker to perform this task well. The lessons learnt from the exercise were that:

- community workers can be trained to make reliable developmental examinations;
- the training needs to have a greater theoretical and scientific content, accompanied by a practical hands-on approach to the observation of children;
- there should be careful monitoring of the trainees' work.

Not surprisingly, mothers fared much better at evaluating their children's problems. Mothers see their children every day and compare them constantly with other children of the same age. They rarely miss a problem, especially when asked questions related to each function.

- Mothers accurately pick up most serious disabilities in their own children.
- A mother's assessment may not be specific to a child's disability. For example, a child with learning difficulties may be identified as not being able to hear well, or vice versa.
- Mothers find it difficult to distinguish between disability and underlying disease or impairment. For example, a child with pus in the ear may be identified as having a hearing disability, when the condition might be one of mild temporary hearing loss accompanying ear infection. On the other hand, it has to be borne in mind that resource constraints may make it impossible for all children with a discharging ear to be covered by a disability-oriented evaluation programme.

- Every child considered by the mother to have a problem should receive a full physical and developmental assessment. The ability of a mother to identify her child's problems should not be underestimated.

**Low-cost rehabilitation**

It is unethical, and probably distressful to the family and stigmatizing for the child, to identify disability while having no plans for rehabilitation. Across the world, community-based solutions are being devised to overcome the limitations of centre-based services, which allow only those living nearby to benefit (5).

The survey findings have led to the development of low-cost advisory services for disabled children and their families at an urban and a rural site. Parents are trained to use pictorial distance training packages dealing with skills in the motor, speech and language, and cognitive areas. The packages, which the parents take home, serve as a reminder for activities. The training involves demonstration and teaching, and mothers are observed handling their children. At the same sites a comparison was made between two groups of young disabled children, one using distance training packages and the other regularly attending a mother and child stimulation group (6).

- The improvement of functional skills in children in the distance training package group was similar to that in the regularly attending group.
- Urban mothers, irrespective of the intervention group, suffered much more from stress than rural mothers at the beginning of the study. Stress had declined considerably in both urban groups by the end of the study.
The majority of the mothers were eager to attend but 85% were prevented from doing so because of household responsibilities and the cost of travelling. There were also cultural barriers inhibiting mothers from travelling alone with their children.

Clearly, distance training package programmes should be reinforced by home visits. These would allow practical help to be given and innovative solutions to be devised for children, and would encourage entire families to take part in the rehabilitation process. Further packages are being developed to include children with vision and hearing problems, and to cover functional abilities in daily life. A pictorial package is being designed to assist children in developing cognitive skills.

**Specialist care in development centres**

About 5% of any population screened in Bangladesh require specialist care. This includes special diagnostic services, consultation with other professionals such as neurosurgeons, and the planning of treatment. The ten-question screening study led to the establishment of the Child Development Centre in Dhaka Shishu Hospital, where, since 1992, several hundred children from all over the country have received specialist care. The work involves paediatricians, psychologists, therapists, social workers and neurophysiologists. There is also networking with professionals from other institutions, including a neurosurgeon, an orthopaedic surgeon, ophthalmologists, and an audiologist.

The philosophy behind the clinical work in this unit is different from that for acute care patients in the hospital. Professionals work towards a long-standing partnership with parents and children. Efforts are made to ensure compliance. Three-quarters of families found that the distance between their homes and the Centre was a significant deterrent to regular attendance. Most parents said they were satisfied with the treatment given. Families were quite happy to buy medicine regularly for children with epilepsy, especially if substantial improvement was achieved.

The Centre now provides training for personnel in other institutions in the country in the field of Developmental Paediatrics and Child Neurology. Training has also been provided to professionals in Nepal and other countries. The Child Development Centre receives supplementary funding from local businessmen. Similar centres may be opened in public institutions elsewhere in the country with help from local entrepreneurs, ensuring that children in poor families receive the help they need.

**Developing services in an urban community**

Severe hostility was encountered at the grass roots when the Child Development Centre indicated that it wished to inaugurate a community-based disability service in a large slum adjacent to the hospital. The major reason for this was the negative behaviour of hospital staff towards the people living there, and the Centre therefore worked hard to build a rapport with them.
The ten-point questionnaire was used in a door-to-door survey of 1000 families. All children found to be potentially in need of disability services were invited to the Centre for assessment, treatment and rehabilitation based on both the Centre and their homes. The families were initially cautious and each one had to be persuaded by a social worker to attend.

In the five years since this project began, many of the initial notions about the community and the objectives have had to be modified. In particular the social development of families and the community, and the general health services for mothers and siblings, have been integrated into the project. Extra space has been allocated for the project in the outpatient department of the hospital. A regular health care and disability service is now operating, and parents attend on the recommendation of friends. The screening process is no longer required as the community itself identifies the children requiring care.

The relative success of the project could be quite unrelated to the disability service per se.

- The screening identified not only children at risk of disability but also families at risk. Social development thus became an integral part of the work. For example, arrangements were made by Centre staff for siblings who required health care, nutritional support and schooling. Work was found for mothers in local factories. Legal aid was provided to victims of child abuse and trafficking and their families.

- Communities do not want impersonal services. Thus, although there was a family planning service in the hospital, mothers were disinclined to use it. However, they now regularly use it through the Centre's social worker, who frequently sees them in their homes.

Insights gained as a result of the community-based approach to disability can be expected to help both the hospital in general and the Child Development Centre's services in particular. A hospital service should never overestimate its own importance and act in an arrogant manner. Attempts should be made to identify the reasons for any unfavourable attitudes towards it among members of the nearest community. A community approach to disability should be adopted as a contribution to raising the quality of life not only of disabled children but also of families as a whole.

Parents with disabled children in Bangladesh are becoming increasingly concerned about their quality of life. A public health approach to the care of such children is necessary if they are all to be reached. It is important to deal with the social factors that lead to disability, such as poverty, social discrimination, and undernutrition. However, once a child is identified as disabled he or she becomes a responsibility of the health sector. Scarce resources should be used to adapt low-cost procedures based in the community and the home which have proved beneficial. Tertiary care is also required but its cost should be borne by local business people.
The concept of avoidable blindness

A major portion of blindness in developing countries either can be cured, or could have been prevented, by a reasonable deployment of skills and resources. This is termed avoidable blindness. Blindness of infectious or nutritional origin can easily be prevented, and visual loss from cataract can be restored by simple surgery. Endemic trachoma and associated infections affect approximately 150 million people in the poorer rural communities of developing countries and can be controlled through hygienic measures such as face-washing, the application of antibiotic ointments in children and corrective lid surgery in adults. Malnutrition resulting in severe vitamin A deficiency can cause permanent blindness by damage to the cornea. This is particularly true in children living under conditions of general malnutrition who are affected by superimposed diseases such as measles, diarrhoea and acute respiratory infections that can aggravate their vitamin A status. Cataract, or opacity of the crystalline lens of the eye, occurs more frequently with advancing age and may affect more than 90% of those over 60 years of age worldwide. Cataract constitutes the major cause of easily curable blindness in most regions, as vision can be restored by simple and effective surgery. The parasitic infection onchocerciasis is a major cause of blindness in some African countries, and is also present in certain areas in Central and South America; control of onchocerciasis, which used to depend solely on control of its blackfly vector, can now also be achieved through the administration of ivermectin to target populations. Blindness due to ocular trauma, a fourth cause of avoidable blindness, can be controlled by preventive efforts at the community level and by early, appropriate treatment. A fifth cause is glaucoma, a group of diseases generally characterized by elevated internal pressure of the eye and resulting in visual impairment. It accounts for about 15% of all blindness. Its control depends on case-detection and treatment with eye drops or surgery.