

DEVELOPMENTAL DISABILITIES

Over the past two decades, there has been a distinct improvement in child survival in India. Secular trends from Sample Registration Scheme data indicate that under five mortality rate is "declining at an average rate of 3% per annum(1). Concern has been expressed that this diminished mortality may simply be adding to the pool of substandard survivors. It is, therefore, logical that urgent attention should be simultaneously directed towards the quality of life in the surviving children. In this context, prevention and treatment of developmental disabilities is a high priority area.

Amongst the several available definitions of developmental disabilities, the following is useful for epidemiological considerations. "Developmental disabilities, a collection of chronic conditions originating in childhood, are manifested as physical, psychological, cognitive, or speech impairments"(2). Examples of these conditions include mental retardation, cerebral palsy, deafness, blindness(3) and locomotor disorders. Developmental disabilities are usually life-long(3).

Reliable national data on the prevalence of various developmental disabilities are scanty even in highly developed

countries(3). A recent national survey of 17,110 children in USA, in broad agreement with the earlier impressions, confirmed the magnitude of the problem(3). An estimated 16.8% (one in six) of US children below 17 years of age were reported to have ever had at least one developmental disability. About 30% of these affected children had more than one developmental disability. The estimated national prevalence of the individual developmental disabilities ranged from approximately 0.2% for cerebral palsy to 6.5% for learning disabilities. Deafness or trouble hearing, delay in growth or development, and emotional or behavioral problems were quite common with prevalences of 3.5%, 4.0%, and 6.1%, respectively. These conditions taken together had a substantial impact on the health and educational functioning of affected children: 1.5 times more doctor visits, 3.5 times more hospital-days, twice the number of school days lost, and a 2.5 fold increase in the likelihood of repeating a grade in school compared with children without these conditions(3).

Similar Indian data is virtually non-existent. Isolated macro (National Sample Survey, 1981-1983) and micro prevalence surveys have been conducted, mostly by non medical personnel(4-9). Firm conclusions based on these surveys are difficult due to variations in methodology, definitions and age groups studied. Nevertheless, it is reasonable to conclude that developmental disabilities are a significant problem in our *milieu* too; the reported prevalences ranging from 5.4% to

15.3% of the entire population. These figures are likely to be underestimates since only the severer disabilities would have been identified by the survey methodology. Further, the spectrum of developmental disabilities is different from the western population. Either visual, mental, orthopedic or speech disabilities have predominated in different reports(4-9). However, a striking feature is the presence of morbidities amenable to simple interventions such as xerophthalmia, poliomyelitis associated lameness, rickets, and birth asphyxia or birth trauma related mental handicap.

Several compelling reasons, therefore, necessitate the need for directing urgent action towards prevention, control and management of developmental disabilities in our context. These include the magnitude of the problem; the human tragedy; the enormous cost in terms of economic and social loss to individuals, families and societies; and the possibility of effective prevention, control and management within our resources and frame work.

Drawing on the vast experience of developed societies, clearly defined principles in the management of a child with developmental delay can be enunciated(10): (i) Multidisciplinary teams are more effective than a therapeutic approach; (ii) The whole development of a child needs to be considered rather than a single deficient area alone; (iii) Home based programmes are more effective in the young preschool child than centre based programmes alone; (iv) Parent involvement in partnership with professionals is essential for sustained progress; (v) Maximum effective-

ness is achieved when parental skills are increased; and (vi) Programmes commencing earlier in preschool years are more effective than those that commence late. This concept has been recently challenged and evidence supports benefits for the disadvantaged rather than the disabled(10,11).

Multidisciplinary team work is the cornerstone of ideal management of children with developmental disabilities. Apart from the Pediatrician, the other vital members of such a team are Therapists, Special educationists, Psychologists, Social Workers, as well as other medical specialists like Pediatric Neurologists, Ophthalmologists, Otorhinolaryngologists, Orthopedicians and Dentists(5). Pediatricians have a central role to perform since often they may be the first or the only professional in contact with young children or their families to school entry(12). The Pediatrician *must*, therefore, become skilled in recognizing, evaluating, managing and referring for additional assessment or community services preschool children with, or at risk for, developmental disabilities(12).

Considering the prohibitive cost and lack of infrastructure and trained specialists, the ideal management of children with developmental delay in our context appears to be an illusion or at best restricted to few isolated centres. It is apparent that bold innovations based on firm scientific footing are essential to offer the best possible under the circumstances. A few pertinent aspects in this context are enumerated below.

Defining the Problem: Urgent community based data is necessary to define

the true extent of developmental disabilities and the relative contribution of different types to plan effective interventions. An insight into the possible etiological factors is imperative before embarking on large scale preventive programmes; the western strategies may not be applicable here. For example, for mental handicaps, birth asphyxia and trauma, iodine deficiency, early childhood infectious diseases (measles, whooping cough, tuberculous or pyogenic meningitis), adverse social situations, and severe malnutrition are important preventable causes in developing countries(13) whereas genetic and metabolic abnormalities may contribute up to 45% in developed countries(14).

Routine Developmental Screening: Despite the uniformity of international opinion on the importance of developmental monitoring for early identification of disabilities, there is no consensus as to how such monitoring should be performed(15). The prominent British and American Pediatric Organizations(16) do not recommend the routine administration of developmental screening tests(15). A process of developmental surveillance(17), which encompasses all primary care activities involved in monitoring child development, has been suggested as a compromise. A feasible integration of child development with other components of child health monitoring is the current goal in the context of developing countries(15).

Developing Culture Appropriate Assessment Tools: Early identification is important because of the potential for improvement of outcome through educational and rehabilitative services for

children with, or at risk for, developmental disability. The most common presentation of a developmental disability is failure to achieve age-appropriate developmental skills(12). The standard development tests are too cumbersome for routine use and need to be simplified and modified to suit the local cultural norms. Local simplified adaptations, requiring minimal or no kit, have been successfully validated and recommended for use by paramedical personnel with minimal training(81,19). The exciting possibility of initiating action through combined psychosocial development and physical growth assessment in a home-based growth and development record is undergoing field trials(13).

Child Development Centers: Tertiary centers offering good facilities are also essential for appropriate referral care and operational research. The nidus of such existing centers in the country(15,19,20) must be widened and replicated. The high risk approach and utility of early intervention in the existing hospital set up has been highlighted(15,19,20).

Parental Participation: The pivotal role of parental participation in management of developmental disabilities is well established in developed societies(10). Parental concern should not simply be met with reassurance, but should be taken as a valuable indicator of either probable developmental problems or the parents needs(21). In the context of developing countries, illiteracy, sub-optimal development stimulating environments and limited trained manpower and resources, argue strongly for a family based care.

Use of Existing Health Infrastructure and Low Cost Technologies: The existing health infrastructure should be utilized for optimal cost effectiveness. The study by Mathur *et al.* (9), published in this issue, has demonstrated the ability of Anganwadi Workers of the Integrated Child Development Services Scheme to detect and prevent childhood disability. The findings need confirmation in diverse conditions before a formal recommendation of national scale programme is envisaged. Similarly, the simple technology of bag and mask resuscitation for management of birth asphyxia is being recommended under the Child Survival and Safe Motherhood Programmes.

In conclusion, urgent efforts should be directed towards prevention, control and management of developmental disabilities and a great deal can be achieved even with our limited resources.

Uday Bodhankar,

*President, Indian Academy of Pediatrics,
(1994),
Near P.O. Dhantoli, Nagpur 440 011.*

G. Shashikala,

*Developmental Neurologist,
Abhyanhxr Nagar, Nagpur 440 010.*

REFERENCES

1. Puri RK, Sachdev HPS. Secular Trends and Determinants of Under Five Mortality Components in India: Implications for Child Survival Strategies. Report Submitted to the Ministry of Health and Family Welfare under USAID Child Survival Programmes, 1991.
2. Yeargin-Allsopp M, Murphy CC, Oakley GP, Sikes K. Metropolitan Atlanta Developmental Disabilities Study Staff. A multiple-source method for studying the prevalence of developmental disabilities in children: The Metropolitan Atlanta Developmental Disabilities Study. *Pediatrics* 1992, 89: 624-630.
3. Boyle CA, Decoufle P, Yeargin-Allsopp M. Prevalence and health impact of developmental disabilities in US children. *Pediatrics* 1994, 93: 399-403.
4. Haxton DP. An Analysis of the Situation of Children in India. New Delhi, United Nations Childrens Fund, 1984, pp 87-92.
5. Singhanian RU. Developmental disorders: Editorial. *Indian J Pediatr* 1992, 59: 29-30.
6. Report on Orientation Course for Anganwadi Workers on Early Detection and Prevention of Childhood Disability, Phase I, Tuglakabad, August 27 and Phase II, Mehrauli October 5-7, 1983. New Delhi, National Institute of Public Co-operation and Child Development, 1983, pp 1-26.
7. Venkatashevari B. Childhood Disability Project Vishakapatnam: A Case Study Presented at the Meeting of Childhood Disability. New Delhi, United Nations Childrens Fund, 1984, pp 1-11.
8. A Pilot Project on Childhood Disability (Prevention, Detection and Rehabilitation). UNICEF Supported Brief Research, Chandigarh, 1983, pp 1-11.
9. Mathur GP, Mathur S, Singh YD, Kushwaha KP, Lele SN. Detection and prevention of childhood disability with the help of Anganwadi workers. *Indian Pediatr* 1995, 32: 773-777.
10. Parry TS. The effectiveness of early intervention: A critical review. *J Pediatr Child Health* 1992, 28: 343-346.

11. Allen MC. The high risk infant. *Pediatr Clin North Am* 1993, 40: 479-490.
 12. Levy SE, Hyman SL. Pediatric assessment of the child with developmental delay. *Pediatr Clin North Am* 1993, 40: 465-477.
 13. Shah PM. Prevention of mental handicaps in children in primary health care. *Bull WHO* 1991,69: 779-789.
 14. Baraister M. Genetic aspect of mental handicap and developmental disabilities. *In: Prevention of Mental Handicap in Developing Countries*. Sheffield, Commonwealth Association for Mental Handicap and Development Disabilities. Ed. Lingam S. Sheffield, Commonwealth Association for Mental Handicap and Development Disabilities, 1986, pp 73-82.
 15. Singhi PD. Early identification of neuro-developmental disorders. *Indian I Pediatr* 1992, 59: 61-71.
 16. Dworkin PH. British and American recommendations for developmental monitoring: The role of surveillance. *Pediatrics* 1989, 84:1000-1010.
 17. Dworkin PH. Development screening—Expecting the impossible? *Pediatrics* 1989, 83: 619-621.
 18. Phatak A. Abbreviated BSID. *In: Developmental Assessment, Follow-up and Intervention in High Risk Neonates*. Ed. Chaudhari S. Proceedings of Workshop held at K.E.M. Hospital, Pune, December 14-15, 1990. New Delhi, Indian Pediatrics, 1990, pp 17-18.
 19. Nair MKC. Neuro developmental follow up of at risk babies. *In: Current Concepts in Pediatrics*. Eds. Puri RK, Sachdev HPS, Choudhury P, Verma IC. New Delhi, Jaypee Brothers Medical Publishers, 1994, pp 351-353.
 20. Bhave S. Organization of hospital based high risk follow up services. *In: Developmental Assessment, Follow-up and Intervention in High Risk Neonates*. Ed. Chaudhari S. Proceedings of Workshop held at K.E.M. Hospital, Pune, December 14-15, 1990. New Delhi, Indian Pediatrics, 1990, pp 5-7.
 21. Glascoe FP. The infant or young child with developmental delay. *New Engl J Med* 1994, 331-56.
-