

Watchwords for management of developmental disabilities in developing countries

With a pooled prevalence of 2.95 per 1000, estimates suggest there are at least 2.5 million people with cerebral palsy in India.¹ Many factors make management and treatment of these people with disability very complex. India is a vast country, with a big rural/urban divide (72% of the population live in rural areas). The lack of competent health care professionals is more marked in rural areas and there are many issues with delivery of care. Though overall rates of literacy are relatively high, there are still huge areas with low literacy levels. Moreover, though poverty has been declining in the last few decades, an estimated 53.5 million people still live in extreme poverty. There is a general paucity of resources and infrastructure, and often a mismatch between needs of people with disabilities and governmental priorities. Although there is increasing clinical research in cerebral palsy in India, it remains focused on interventions to reduce impairment; whereas activities, participation, and environmental factors are minimally addressed.²

Similar to the 'F-words' (function, family, fitness, fun, friends, and future) which have been suggested as a universal approach for childhood disability,³ seven 'watchwords' are proposed to summarize the actions we need to take. These watchwords are: access, empowerment, inclusion, leadership, research, surveillance, and workforce.

'Access' to health care is a primary issue. The vast land area, huge population, large rural/urban divide, lack of facilities, financial constraints, and an overburdened public health care system (and an expensive private one) make it difficult for a large percentage of families to gain access to appropriate health care. A lack of qualified personnel is a big constraint in rural and some urban areas. Delivery of service is closely linked to access. The Rashtriya Bal Swasthya Karyakram, a Government of India initiative,⁴ aims to detect developmental disabilities in early childhood by trained health care workers. A system of linkages allow referral, from the rural to the tertiary care institutions.

'Empowerment' of disabled people and their families exists only marginally in India. Patients and families need to be recognized as equal partners and an extension of the medical team. A move to adopt India's regional languages for purposes of education and communication may yield better results.

'Inclusion' is far from the daily reality of most disabled people. Mainstreaming into school and work is riddled with prejudices in resource-poor countries. It is a very broad term for

creating an environment promoting activity and participation, and closely linked to societal attitudes and governmental policy.

'Leadership' issues are severe, with problems of direction and coordination. Voluntary leadership of teams and communities, and leadership for good governance are sorely needed. Mentoring young talent for leadership is essential.

'Research' into evidence-based practices, cost-effective solutions, optimization of resources, use of new technology, local adaptation, and innovation, are all vital for finding the best solutions for a given scenario.

'Surveillance' has been an almost completely neglected area and becomes even more important for preventing complications. This cannot be overemphasized. The Indian Academy of Cerebral Palsy has taken the lead in bringing together all stakeholders to design India's first Cerebral Palsy Hip Surveillance Program.⁵ It is also developing a National Database on Childhood Disabilities. These initiatives are welcome, but implementation will require the involvement of both the government and the voluntary sector, and huge financial outlays.

Finally, 'workforce' development for disability management should concern everyone in this field, even more so in resource-poor countries. Both the medical and paramedical workforce need development. Creation, education, and coordination of multidisciplinary teams representing different specialties is essential.

Watchwords such as these are important to remind us of the multifaceted strategies required to successfully manage developmental disabilities in resource-poor countries.

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