Childhood Disability – Our Responsibility

S SACHIDANANDA KAMATH
National President, Indian Academy of Pediatrics, 2015.
drsskamath@gmail.com

The optimal development of the child must be ensured during the early years by avoiding – as much as possible – perinatal, genetic, metabolic and environmental risk factors. Globally, about 200 million children do not reach their developmental potential in the first five years because of poverty, poor health, nutrition and lack of early stimulation. The World Health Organization estimates that 15-20% of children, worldwide, have disabilities; 85% of which are in developing countries [1]. As per 2011 Census of India, there are 7,862,921 children with disability in the below 19 year age group, including 1,410,158 visual impairment, 1,594,249 hearing impairment, 683,702 speech disorder, 1,045,656 movement disorder, 595,089 intellectual disability, 678,441 multiple disability, and 1,719,845 other disabilities [2].

Most information on prevalence of childhood disability emerges from small scale studies. In a state-wide *Aanganwadi*-based systematic sample survey in partnership with IAP Kerala, 2.5-3.4% of children had various forms of developmental problems as diagnosed by using screening tools [3,4]. The most common forms were: developmental delay (69.3%), speech delay (14.3%), global delay (5.7%), gross motor delay (5.3%) and hearing impairment (3.6%). The prevalence rate of autism spectrum disorder (ASD) is estimated to be 1 in 500 and incidence rate is approximately 1 in 91 000 people in India [4]. The prevalence rate of attention deficit hyperactivity disorder (ADHD), a condition almost always associated with poor academic performance, was 11.3% among primary school children; behavioral difficulties were found in 36.11% of the children with ADHD [5].

Hearing and visual impairments are other disabilities that affect quality of life of children, and require some form of special education services. Obviously, limited opportunities exist for these individuals to learn through communication, visual elements, and the people around them. Vision screening of school children in developing countries could be useful in detecting correctable causes of poor vision, especially refractive errors, and in minimizing long term permanent visual disability [6].

All of us would agree that data from isolated studies in different parts of the country would not be sufficient to push for a policy change, and we need reliable data at the national level, using the best available research methods. Recently, International Clinical Epidemiology Network (INCLEN) under the leadership of MKC Nair and NK Arora conducted studies to estimate the prevalence of neurodevelopmental Disorders (NDDs) among children aged 2-9 years, among urban, rural, hilly areas, and tribal communities in India. Data from 4000 families from 6 regions of India revealed that 10-18% of children aged 2-9 years from rural/urban/hilly areas had one or more NDD. The prevalence in tribals was lesser (5%), perhaps reflecting lower infant and child survival [7].

With increasing focus on developmental disorders, the Government of India has undertaken two initiatives: questions regarding disability were included for the first time in the 2011 Census of India; and a national program for screening, diagnosis and treatment of NDDs – the *Rashtriya Bal Swasthya Karyakram* (RBSK) – was launched in 2013, with focus on district intervention centers. As comprehensive child health care implies assurance of extensive health services for all children from birth to 18 years of age, RBSK addresses diseases and deficiencies in addition to defects and disability. Universal screening should lead to early detection and timely intervention of medical conditions, ultimately leading to a reduction in mortality, morbidity and lifelong disability. The dividends of early intervention would be huge, including improvement of survival, reduction of malnutrition, enhancement of cognitive development, educational attainment, and overall improvement of quality of life of our citizens. It is our duty and responsibility to support and partner with the central and state governments to implement the program in right earnest.

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