

1. Education of Children with Disabilities due to Chronic Health Impairments: Case studies

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ABSTRACT

Chronic Health Impairments (CHIs) are long-term or permanent medical conditions that impact everyday life of individuals. The present study concentrates on the Chronic Health Impairments (Neurological Disorders and Blood Disorders) causing disabilities in Children as specified in the Rights of Persons with Disabilities Act, 2016. The RPwD Act, 2016 has included the Chronic Neurological Disorders namely, Multiple Sclerosis (MS) and Chronic Blood Disorders, namely, Haemophilia (HA), Thalassemia (THAL) and Sickle Cell Disease (SCD). Objectives of the study were to explore the nature and severity of chronic health impairments (MS, HA THAL, SCD) causing disability in children and to study the efficacy of existing educational interventions programmes. The design of this study was qualitative (single case design) in nature. Altogether 27 (12 girls and 15 boys) profile studies comprised of 2 participants of Multiple Sclerosis, 10 participants of Haemophilia, 9 participants of Thalassemia, and 6 participants of Sickle Cell Disease had been undertaken from 5 different states (Delhi, Gujarat, Maharashtra, Punjab and Odisha) of India. Five self-designed research tools viz. Child Profile Sheet having items related to socio- demographic-clinical profile of the child, Interview Schedule for Parents, Child and Health Care Providers having items related to the child's health, his illness, treatment, child's engagement in day to day activities, education and overall management of the disorder and a Questionnaire for Teachers having items related to the child's education, his/her participation in school activities and learning, difficulties faced by the child and teachers, teaching-learning strategies implied and their effectiveness etc. Information about the participants in this study was mainly collected through interaction with the participating children with CHIs, teachers, school head/principal, family and related members (parents, siblings, grandparents, uncle, aunt etc.),

doctors, special educators as well as inclusive education coordinators of the respective state and district and functionaries of NGOs, wherever available. Qualitative analysis of information revealed that children living with CHIs had been missing substantial periods of schooling to attend their treatments, and struggling with complications of these disorders. There was no definition of 'Persistent absenteeism' or 'chronic absenteeism' exists in Indian policies and programmes related to school education. These periods of absence demands special initiatives from schools to support children in covering up the missed contents and activities of the class. Health care providers were not in a position to specify the educational consequences of a specific chronic impairment. The school teachers needed assistance in obtaining health related information with respect to children with CHIs since there were absolute lack of knowledge among teachers on care, education and management of Children with CHIs in school. This led to undermine the safe care, equality and provision of quality education to Children with CHIs. A nationwide in-service teacher preparation programme is required to be initiated for improving awareness, information, knowledge and awareness among the working teachers in schools. For the prospective teachers, the frame work of curriculum for teacher education programme and contents of the curriculum needs to be reviewed in the light of preparing teachers for meeting the challenges of children with CHIs in their classes and schools. There is also a need of comprehensive guidelines for school personnel and parents for better care, education and management of Children with Chronic Health Impairments as specified in the Rights of Persons with Disabilities Act, 2016.