

Social participation of parents caring for a child with profound disabilities in developing countries: Evidences from Bangladesh

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ABSTRACT

Parents caring for a child with a profound disability encounter different experiences compared to the parents caring for a child without disability. The aim of this paper is to develop a greater understanding of the social participation of parents caring for a child with profound disabilities in the context of developing countries with special reference to Bangladesh. This study is qualitative in nature and adopted Interpretative Phenomenological Analysis to explore the parents' subjective experiences of the social participation. Research data were collected from September 2016 to February 2017 using semi-structured interviews with 13 pairs of parents caring for a child with significant disability. The study reveals that parenting a child with disabilities restricts the parents' participation in the greater society because of the association of shame and stigma with disability. In addition, parents had to give up employment, limit contact with the kinship network and avoid social events as they were unable to manage time due to the additional caregiving burden. Moreover, government and non-government services for children with disabilities in the developing countries are very limited. Furthermore, the information about the services is also not available to the parents. Therefore, parents find it difficult to cope with the challenges that lead to the alienation of the parents. The paper recommended some strategies to address those issues in the context of Bangladesh, which in turn might be applicable to the developing countries as well. The paper has policy implications for the international agencies to design their working strategies while working in the developing countries.

Keywords: Caring, Parenting, Profound disability, Social Participation, Bangladesh.