

A Qualitative Study to Explore the Social Perception and Stigma around Disability, and Its Impact on the Caring Experiences of Mothers of Children with Physical Disability in Bangladesh

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Abstract : Across the globe more than a billion people live with a disability and a further billion people, mostly carers, are indirectly impacted. While prevalence data is problematic, it is estimated that more than 15% of the population in Bangladesh live with a disability. Disability service infrastructure in Bangladesh is under-developed; and consequently, the onus of care falls on family, especially on mothers. Within the caring role, mothers encounter many challenging experiences which are not only due to the lack of support delivered through the Bangladeshi health care system but also related to the existence of stigma and perception around disability in the Bangladeshi society. Within this perception, the causes of disability are mostly associated with 'God's will'; 'possession of ghosts on the disabled person'; and 'karma or the result of past sins of the family members especially the mothers'. These beliefs are likely to have a significant impact on the well-being of mothers and their caring experience of children with disability. This is an ongoing qualitative study which is conducting in-depth interviews with 30 mothers from five districts (Dhaka, Mymensingh, Manikganj, Tangail, and Gazipur) of Bangladesh with the aim to explore the impact of social perception and stigma around physical disability on the caring role of the mothers of children with physical disability. The major findings of this study show that the social perception around disability and the social expectation from a mother regarding her caring role have a huge impact on the well-being of mothers. Mothers are mostly expected to take their child on their lap to prove that they are 'good mother'. These practices of lifting their children with physical disability and keeping them on the lap for a long time often cause chronic back pain of the mothers. Existing social beliefs consider disability as a 'curse' and punishment for the 'sins' of the family members, most often by the mother. Mothers are blamed if they give birth to 'abnormal' children. This social construction creates stigma, and thus, the caring responsibility of mothers become more challenging. It also encourages the family and mothers to hide their children from the society and to avoid seeking accessible disability services. The mothers also compromise their careers and social interaction as they have to stay with their children at home, and that has a significant impact on personal wellbeing, income, and empowerment of the mothers. The research is informed by intersectional theory and employed an interpretive phenomenological methodology to explore mothers' experience of caring their children with physical disability, and the contribution and impact of key relationships within the family and the intersection with community and services.

Keywords : mother, family carer, physical disability, children, social stigma, key relationship

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