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Title of the Thesis : The Social World of the Children of the Leprosy-affected Parents

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Leprosy is a medico social public health problem. At one time it was prevalent across the world and was greatly feared as a progressive disease which mutilated and disfigured human body. For centuries mankind shunned its sufferers and cut them away from mainstream society to live in remote islands and isolated buildings. The disease made its sufferer forego his ascribed status and achievements in the society and accorded him social death. Incidence of societal discrimination against leprosy afflicted and public apathy to their suffering is neither history nor restricted to distant territories but it is something which is happening even today in our society. Leprosy afflicted are not only shunned when they are alive, but they are treated as outcast even after their death. Members of their family (including children) also face societal discrimination.

The Constitution of India and other international instruments binding on its citizenry and governance have adequate provisions to ensure that its children grow happily in healthy and discrimination free environment, yet there is a section of Indian children who are growing up in segregated colonies under impoverishing and disabling conditions. Born to leprosy afflicted parents, such children are living at the margins of the society in segregated leprosy settlements at the outskirts of cities and townships, amid scarcity and appalling conditions.

The present study explores the social world of such disadvantaged children making use of *Bronfenbrenner's Bio Ecological Model of Human Development* and assuming that a child's social world ranges from his immediate environment to the broadest social context. The study delves into their lived experiences and living conditions. The study is limited to Delhi and research participants include : a) children of leprosy affected parents, b) leprosy affected parents and c) non infected community population.

The present study is a pointer to the fact that leprosy disproportionately affects the poor. The physical limitation imposed by advancing leprosy usually results in loss of job or

underemployment for the parent and cause economic distress to the family. As a consequence many children in school going age start acting as accomplice to their parent in begging or take up paid work in informal sector. In addition to attending to economic needs, children also take care of their leprosy affected parent. Few children who attended school reported prejudiced behavior of teaching staff and narrated several instances of discrimination and corporal punishment in the school.

Leprosy affected parents reported stigma in the form of shame and disgrace, negative stereotyping and name calling. They also noted unfair treatment, denial of services and entitlements and social distancing for themselves and their family members in the community. Although parents held positive attitude towards schooling, their desire to send children to school got buried under economic compulsion and family needs.

The study shows that even in this age of information and technology, public hold stigmatizing and discriminatory attitudes towards leprosy affected individuals and their families. Public refuse to buy newspaper and sealed food packets sold by leprosy cured person. Owners of houses refuse to rent out a portion of their house to them. Common man feel uncomfortable when travelling in public transport with them and do not want to work with them and continue to believe that leprosy patients need to be kept separately in segregated settlements.

Thus the challenges faced by leprosy affected individuals and their families are not restricted to disease specific physical impairments but also include the social stigma associated with the disease which forbid their access to community resources. It muffles their voice from being heard by planners and policy makers. So appropriate legislative interventions, awareness building programmes and welfare measures should be undertaken to promote their social reintegration. At the same time it is to be kept in mind that the family is the main source of care and support to a child. It holds the greatest potential for protecting a child from all forms of discrimination, abuse and violence. Hence wards of leprosy affected parents should not be separated from their parents to be kept in institutionalized care. Instead suitable measures should be adopted in a manner that ensures upliftment and integration of both the parent as well as the child into the mainstream society.
