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Title of the Thesis: Human Rights Entitlements of Children with Disability with Special Reference to Parents Perceptions

Disability has been a part of society since mankind has existed. It is an occurrence touching people's lives in many different ways. While some people are born with it or experience disability as children, most people become familiar with it later in life. It is a functional limitation or restriction of an individual's ability to perform an activity (WHO, 1980).

The realization of human rights of children with disability requires that parents understand what the rights are, how these can be ensured for their children, have (or develop) the capacity to use them for the benefit of their children. The objectives of the study are as follows:

1. To study the awareness that parents have of human rights entitlements of their children with disability.
2. To understand parents' awareness of services and programmes which they have availed for their children with disability.
3. To explore the initiatives which parents have taken to secure rights of their children with disability, and
4. To understand the role played by care providers in organizations and special schools in awareness levels of the parents on rights of children with disability.

The study was based in Mumbai as it has the widest representation of people from all socio-economic levels, several occupations, varied educational levels, regional origins, religious backgrounds, as well as large number of special schools and organizations providing services to children with disability. These factors ensured a sample which would adequately represent the population of India. The universe consists of all parents of children between 6 to 14 years of age with disability (with visual impairment, hearing impairment, orthopaedic impairment and mental retardation) availing of services being provided by the governmental or non-governmental organizations and special schools for disabled children in the metropolis of Mumbai. The sample of parents has been drawn using two-stage stratified random sampling technique. The interview schedule was administered on 275 parents. Further 60 parents participated in Focus Group Discussions. In addition to this, 49 professional care providers from eight special schools and organization were interviewed to shed light on their awareness on entitlement to human rights of children with disability. The objective of including care providers as a separate set for data collection was to find out if their awareness and knowledge of human rights entitlements of children with disability is likely to get transferred to parents

of children with disability through interactions. Therefore the total number of respondents including parents and care providers was 384.

Awareness scores of parents were calculated to make a comparative analysis of parent's awareness on different personal and socio-economic factors to enable a smooth analysis of quantitative data. Then, average awareness score is worked out factor-wise. Further, an attempt is made to identify the factors (i.e. parents' attributes, socio-economic factors and Childs' attributes) which significantly affect the awareness level of the parents as regards the rights of the disabled child. In order to find out if there was a group of factors together (rather than individually) making a significant impact on parents awareness level from among 14 factors mentioned above a decision/classification tree method is used. For analysing the data gathered from professional care providers, descriptive statistics has been used.

Rights of Children with Disability

The basic analysis of data has brought to light that the right to identity, citizenship and nationality has been fulfilled for 97 percent of children with disability in the sample. Another fact that came out was that parents view their children, both disabled and non-disabled as equals and do not discriminate against children with disability in these matters. Parents who are treating their disabled child at par with other children are also the ones who would go ahead and advocate for as well as demand rights entitlements for them.

Most of the parents (93 per cent) know from their experience that they cannot depend on others for support while bringing up their disabled children and hence they do not expect any help, support or assistance from any quarter. A very small section of parents (i.e. 7 per cent) felt that all the constituents' i.e. self, family, community and government are jointly responsible for development of children with disability. These parents probably have a healthy self-esteem and have not allowed any sense of guilt to develop within them for having a child with disability. As far as the specific steps for development of disabled children is concerned the parents could only think of education and training for their children and some parents had not yet given it any thought. The right to development as a concept where several stakeholders are responsible for ensuring the provision of conditions at different levels beginning with the parents, family, immediate community, local self government, state government and central government are required to be jointly cooperating amongst themselves has not even occurred to any parent. Half the parents and their children are facing discrimination on account of disability.

With respect to disabled child's right to participation, it was found that parents believed in their disabled child's evolving capacity. With the kind of situation in India about rights of children being violated in many ways and right to participate in matters related to their lives and future, it is good trend that 34 percent parents sought their children's views. Parents do contemplate at times on the impact of their decisions on the child but including them in discussions while making decisions is not a common feature of Indian families, which was corroborated by the data.

The fact that most of the parents had acquired a disability certificate for their child indicates that parents have taken the most basic and important step towards securing their disabled child's rights, since it opens many doors for availing the benefits and services available to disabled children, both from government and non-governmental organizations.

Most of the parents were not aware of the educational scholarship for disabled children. The parents are also not even aware of inclusive education policy of the government of India. A high percentage (45 per cent) of parents and their children with disability are experiencing discrimination. The fact that almost half of the sample of children with disability is facing different degrees of discrimination is a cause for concern. It is a gross violation of right of a child to grow in an environment which is caring and supportive.

Parents already are at a certain level of awareness in terms of having knowledge of what is available for their children. In terms of taking steps to secure rights of disabled children with respect to services provided for children with disability parents had not given it any thought. Even if they have not availed of the services, the fact they made efforts is indicative of some amount of awareness of their child's entitlements.

Factors Showing a Significant Impact on Awareness Levels of Parents

The classification tree method and data collated and presented in graphs and figures have brought to light that parents' educational level has a positive relationship with the awareness scores which means that higher the level of educational attainment, higher is the parents' awareness score. The type of child's disability is another factor which came up indicating significant importance as far as having an impact on the awareness of the parents is concerned. One more factor which has been found to be of significance is the birth order of the child with disability, where parents of disabled children who are the eldest have higher awareness scores than children who are youngest or from other ranks. Similarly, number of children was also found to have a significant impact of awareness level of the parents of child with disability. Parents with two children are more aware as compared with other parents, which could be on account of their maturity gained through experience. Further parents having more than three children are found to be least aware.

Cross Effect of Gender and Education Attainment on Awareness Level of Respondents

It was observed that male respondents were generally found to have higher variability in the awareness score. However, mean awareness score of illiterate female respondents was found to be higher than illiterate male respondents. Same pattern was observed in case of female respondents having education attainment between Std. 9-10, Std. 11-12 and graduate level. This clearly indicates that female respondents were found to be more aware than their male counterparts keeping the education level the same.

Impact of Institutions and Care Providers on Parents Awareness

Institutions

From results of the classification tree method, it is observed that awareness score of parents does get affected with the location where parents are taking their disabled children for education or other services i.e. Special School / Organisation.

Care Providers

Awareness scores for care providers from a particular special school / organization were calculated and a comparative analysis of the same was made with awareness scores of parents availing of services from the same school or organization. The comparison revealed that average awareness score of care providers is generally higher than parents of the children belonging to the respective organizations/special schools except in the few cases.

The correlation coefficient between average awareness scores of care-providers and respondent parents of corresponding organizations/special schools is found to be negative. This means that channel of transmission of information on awareness of rights of child with disability is not working effectively at the grass root level since, communication or information exchange between care-providers and parents is ineffective even in a metropolis like Mumbai. This revelation has very serious implication which indicates that the care providers and parent's interactions are not directed towards parents gaining information or knowledge that can lead to building their awareness for seeking rights of their children with disabilities.