Assessment of Awareness Levels of Parents – A Multivariate Approach

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Abstract Disability is a complex, and dynamic phenomenon impacting lives of children afflicted with it, in numerous ways. Conventionally children with disability have been relegated to the margins, both within the child rights agenda and disability rights movement. Their dependence on parents for fulfillment of basic needs and human rights entitlements provides the basis for parents having to take on the responsibility to ensure the same. Parents can take action leading to fulfillment of entitlements based on their awareness of available information, services and facilities. The study aims to find out the level of parents awareness with respect to human rights entitlements of their children. It discusses the detailed methodology applied in this study for assessment of awareness levels of parents. This study lends itself to the use of a quantitative paradigm as the findings allow for generalization using a large sample size and the work pre supposes that parents' awareness of rights of Children with Disabilities is affected by (i) personal factors of Parent (i.e. age, sex, religion, educational attainment, occupation) (ii) socio-economic factors such as number of children and nature of family, family income, per capita income) and (iii) factors relating to child with disability (i.e. age, sex, type of disability, age at the onset of disability and birth order of child in the family). A decision tree method is used to establish the dominant factors from among the personal and socio-economic factors of respondent parents which impact the awareness level of parents of child with disability. From the decision tree method, it is established that parents' education attainment is the most dominant factor affecting their awareness levels. From the remaining factors, birth order of the child in the family, child's type of disability and number of children in the family are also dominant factors affecting awareness of respondent parent of rights of child with disability.

Keywords Human Rights, Disability, Children with Disability, Parents

impacting lives of children afflicted with it, in numerous ways resulting in their vulnerability. The needs and rights of children with disabilities are frequently overlooked, as they experience double invisibility – that of being a child and a disabled individual. This is corroborated by the United Nations Convention on the Rights of Persons with Disability (UNCRPD), 2006 [2] which states that children with disabilities are often subsumed with in the category of people with disabilities. Vulnerability among children with disabilities is very common since disabilities are barriers to accessing their rights entitlements. These barriers are created by interaction of discriminatory attitudes, actions, cultures, policies, institutional practices and lack of political will. This research study attempts to explore whether children with disability are able to access their human rights entitlements. The United Nations Convention on the Rights of the Child (UNCRC), 1989 gives legal expression to the notion that children have independent human rights and for the purpose of this research study UNCRC has been taken as the basis for examining the fulfillment of human rights entitlements of children with disability. Therefore this study is located within the canvas of human rights entitlements of children with disability.

Children with disability need rights entitlements because they are dependent, and in the formative period of their lives. The developmental state of children makes them particularly susceptible to the conditions under which they may live. Adequate conditions must be provided to them for the realization of their potential. These adequate conditions are a prerequisite for fulfilling entitlements of children as mandated by the UNCRC. The rights entitlements which are significant to this study are (i) right to identity and nationality; (ii) development rights including right to health, education, family environment and parental care, play and recreation; (iii) right to non-discrimination; and (iv) participation rights including the right to have a say in decisions that affect them, have a say in family decisions, participation in public life through access to public places, as well as public services.

Conventionally children with disability have been relegated to the margins, both within the child rights agenda and disability rights movement. To make matters worse

1. Introduction

Disability is a complex, and dynamic phenomenon

children lack awareness of their rights, and have inherent limitations in advocating for their own cause without adult mediation. Their dependence on adults, for fulfillment of basic needs and human rights entitlements becomes the basis for parents having to take on the responsibility to ensure the same. For children, parents are the pillars of information and strength, who strive to ensure availability of conditions necessary for optimum development of their children. They can take action leading to fulfillment of entitlements on the basis of their awareness of available information, services and facilities.

A question which is pertinent to this study is whether parents of children with disability are aware of human rights entitlements ensuring their children certain minimum conditions for their growth and development. The other question that follows from the first is whether parents have any awareness on the rights entitlements committed by the government of India through its ratification of the UNCRC, in 1992. Hence parents' awareness of the fact that all children including children with disability must be provided with opportunities that enable them to grow and develop to maximum extent possible is of critical significance. As children are dependent on their parents, the research study has attempted to find out the ground realities in terms of awareness parents have of human rights entitlements of their children with disabilities; whether these rights are accessible to their children; and have any of them taken any initiatives to secure these rights for their children.

There are several studies describing various aspects of lives of parents of children with disability. Literature is replete with data and research on parents' reactions to the birth of child with disability, stress related to caring for child with disability and stressors thereof, the efforts parents make in coping with stress, and some positive coping outcomes of rearing disabled children. It neither has information nor data on parents' awareness of rights entitlements of their children with disability nor any mention of parents' initiatives to secure entitlements for their children. The review of literature revealed lack of research studies on parents' understanding of and efforts to ensure realization of human rights entitlements of their children.

This paper presents a methodology for assessing parents' awareness levels with respect to the human rights entitlements of the children with disabilities. In addition an effort has also been made to identify the dominant factors (from among the personal factors of parents, socio-economic factors and factors relating to child with disability) which have an impact on parents' awareness levels using the t-test, F-test and classification tree method.

2. Context of the Study

To be born human is to have human rights which are based on respect for the dignity and worth of each person, both as individuals and as members of a community, group or, of society as a whole. Human Rights are universal and must be

equally applicable for all people regardless of age, gender, caste, class, religion, ability or disability. These are intrinsic to human development and human development is a means to realizing human rights. Human development focuses on developing an enabling environment in which people can enhance their capabilities, take part in decision making and make their choices. While human rights are ultimately matters of individual entitlements, their fulfillment depends on the social environment and conducive conditions.

The realization of human rights requires that people understand what their rights are and that; they should have the capacity to use them for their own benefit. All such rights become meaningless if the circumstances in which people live make their realization impossible, as it happens most frequently with people with disabilities. Inevitably, the very people who need these rights the most, are, unable through personal and or social circumstances, to use them.

Full participation within the basic units of society – family, social groups and community – is the essence of human experience and human rights realization. The right to equality of opportunity for such participation is set forth in the Universal Declaration of Human Rights (1948) and should apply to all people, including those with disabilities. In reality however, disabled persons are often denied opportunities of full participation in the activities of the socio-cultural system of which they are a part. This deprivation comes through physical and social barriers that have evolved from ignorance, indifference and fear [2].

Disability is a relative term, since different cultures define their norms differently. Concepts of disability are therefore situation bound, contextual, and can be subjective [3-4]. In a tradition bound society like India, stratified by caste, class, religion, rich and poor, male and female, societal attitudes can disable a person [4-5]. Disability is regarded as taboo, a retribution for past sins committed, stigmatizing a child, and cutting across economic boundaries. Persons with disabilities suffer from discrimination based on society's prejudice and ignorance. In addition, they often do not enjoy the same opportunities as other people due to lack of access to essential services. Every day people with disabilities are denied their right to express themselves, to make choices, and to obtain access to education, employment and healthcare. Robinson [6] states that persons with disabilities frequently live in deplorable conditions, and face physical and social barriers, which prevent their integration and full participation in the community. As, a result, millions of adults and children throughout the world are segregated, deprived of virtually all their rights, and sometimes lead wretched lives. Therefore, disability is a human rights issue.

The rights of the disabled citizens are the same as those of non-disabled citizens. However, the promotion and protection of human rights of people with disabilities is a continuing struggle. Many disabled people are isolated socially, and/or physically, and according to Harris [7] learning about their human rights including the most basic right to have some say and control over their own lives, has been the first step towards self-liberation for people with

disabilities.

3. Rationale for the Study

Childhood is a crucial stage of human development as it is the most formative period in the life of any individual. The developmental state of children makes them particularly susceptible to the conditions under which they may live – whether it is poor food, violence, discrimination or a supportive, loving and stimulating environment. Children are initially totally dependent. They can grow towards independence only with the help of adults.

As today's children are the citizens of tomorrow's world, their survival, protection and development is the prerequisite for safeguarding the future development of humanity. Enabling the children to realize their fullest potential equips the younger generation with knowledge and resources to meet their basic human needs. For the children to grow to their full potential, should be a primary goal of national development. Child rights' in India is an issue, which is rarely talked about even though we ratified the UNCRC in 1992. Children are not seen as a separate group with distinct rights and issues of their own and despite being a signatory, these rights are hardly ever enforced in India.

The problems faced by children with disabilities are primarily the question of their human rights i.e. the availability of conditions for the development of their innate characteristics and the realization of their potentials. One may identify a host of physical and social barriers, which prevent their integration and full participation in social life. There is a greater need to focus attention on the social, economic and cultural mechanisms, which create barriers for children with disability to live a meaningful and productive life. There is also a need to look at the multidimensional characteristic of the processes by which, they are kept away from social exchanges, policies and rights, which are an intrinsic part of social and economic participation. Parents play a very significant role in ensuring their children's participation in social processes at all levels. They have the responsibility to procure services for their children. They also have the maximum amount of knowledge with regards to their children. This knowledge may not be available with other people which is also the basis for their action towards seeking services, securing entitlements for their children. Parents are the best advocates for their children since they are most closely associated with them.

Parents of children with disability are no different from parents of typical children. They have strengths and weaknesses like everyone else. However, parents of children with disability are the prime targets of societal reaction, are required to make self-adjustments and have responsibility to procure services for their child. Parents play a dual role in the life of child with disability. One as duty bearers to make provisions for their child's growth and development and the other as advocates seeking from the rest of the duty bearers (i.e. institutions, NGOs and the government at the local, state

and central level) services and provisions required by their children with disability, both as other children and the special requirements on account of their disabilities to bring them at par with children who are not disabled.

Thus the research undertaken proposed to learn the awareness that parents have on human rights entitlements of children with disabilities; the specific rights that children with disabilities have been able to access or not access; explore the initiatives that parents may have taken to secure some of these rights; and finally design strategies to promote human rights awareness among parents. The research study focuses on parents since children with disability are, more than other children, dependent on their parents for their basic as well as higher order needs. Moreover, parent's awareness and efforts to access rights for their children will inevitably/ultimately lead to awareness growing among children themselves. It is hoped that these children will grow up as aware and well-adjusted adults. Professional interventions for parents of children with disability rarely include a component on human rights aspects of their child's development requirements.

Review of literature in the Indian context shows that there is dearth of any kind of research on rights of children with disability. There are some articles written on the right to education of children for children with disability with specific reference to inclusive education as compared with segregated education. There is a need to take up a research study, focusing on rights of children with disability, with a much wider focus i.e. in the areas of survival, development, protection and participation. This is envisaged in the purview of the proposed research study.

4. Review of Literature

Literature was reviewed for research studies on parents of children with disability; examining situational context of children with disability, rights of children and barriers to realizing the same, the constitutional provisions as well as policies and programmes of government of India relevant to disabled children which lead to their human rights fulfillment. There are several studies on parents' reactions to disability in their child, pressures and stresses due to the presence of child with disability, their coping mechanisms, and impact on marital relations of parents; experiences of children with disability, government of India policy and programmes and their analysis. However, studies examining parents' awareness on rights entitlements of their children with disability could not be found, and thus the need for this research study.

Parents of Children with Disability

Austin [8] suggests that parents often feel totally unprepared and overwhelmed by the responsibility and needs of caring for a disabled child. They experience a multitude of emotions and must eventually learn to accept the fact that their lives have changed profoundly and permanently. Since

attitudes towards people with disabilities continue to be influenced by negative stereotypes [9-10], confronting the birth of a child with disability challenges most parents' belief systems. As parents confront disability in their child, they must also cope with their beliefs about what and who can influence the course of events. Their views will influence their interpretation of events related to the disability, their help seeking behaviour, and their approach to care giving [11].

Kumar's [12] research has indicated that families who are successful in coping with a disabled child are able to mobilize their internal and external means of support to deal effectively with the special needs of their child. A study by Taanila et al [13] found that child with disability affects the everyday life of the family in terms of change in parents' social relationships, work, career or leisure-time activities, while simultaneously such families are subject to the same pressures and tensions that every family faces in the modern society. The literature is uniform in reporting that families of children with disabilities experience high levels of stress [14-15]. It is also noted that having a child with disability affects not only the parents, but also siblings and the relationships among the family members.

Glenn [16] found that alongside the pressures that all parents experience, couples caring for a child with disability are faced with additional challenges, including, managing more traditional parenting roles; a lack of time for each other; managing different coping styles; coming to terms with loss and grief; adjusting to changes over time; the care demands specific to their child with disability; and acute financial pressures. A study on health and wellbeing of parents [17] indicated that practical day-to-day care demands of the child with disability created challenges for parents. The parents are plagued with feelings of pessimism, hostility, and shame [18]. Denial, projection of blame, guilt, grief, withdrawal, rejection, and acceptance are the usual parental reactions [19]. Some parents also experience helplessness, feelings of inadequacy, anger, shock and guilt whereas others go through periods of disbelief, depression, and self-blame. The siblings also experience feelings of guilt, shame, and embarrassment [20]. Studies comparing mothers of children with disability and those without disability found levels of stress higher in mothers with disabled children [21-23]. High level of stress in parents was attributed to feeling of being restricted, social isolation and dissatisfaction [22].

Risdal and Singer [24] analyzed the findings of a number of different studies involving families of children with genetic, physical or developmental disabilities. They found that couples with a child with disability had poorer marital adjustment. Glenn [16] has discussed that couples raising a child with disability are at a greater risk of divorce or separation than couples raising a child without disability. She further suggests that there is a possibility of parents getting trapped in a vicious cycle of poor relationships and impaired parenting, a cycle involving a perceived lack of support, increasing conflict, challenged parenting and a detrimental impact on the health and well-being of all

members. However, a study by Holmbeck et al [25] did not find any difference in marital satisfaction of parents of children with Spina Bifida and those without disability.

Majority of the literature with respect to parents of children with disability has highlighted the stresses and the subsequent negative consequences in caring for a child with a disability [17, 26-27]. Primary focus within this literature is on stress, strain and grieving. Although many researchers have found that the families of children with disabilities report more stress than other families, recent research shows that some families also report some positive feelings or perceptions.

Mahoney [28] documented positive effects. He found that the disabled child can have an integrative effect by focusing the family's energy in a concerned, loving manner, thereby minimizing some of the other day to day problems. Recent studies have consistently reported that families with a child with disabilities can and in fact do have positive perceptions which lead to better quality of life for the family, and scope for maximizing the child's potential. Studies have been made recognizing that many families have been successful in developing positive perceptions regarding raising a child with disabilities [29-31]. Findings from a study by Gupta and Singhal [20] show that though precipitated by a specific event, formation of positive perceptions is usually a process, which can occur simultaneously or a long time after the event. Some parents expressed a new appreciation for life and ordinary things they used to take for granted.

Children with Disability

Children with disability suffer unnecessarily due to false beliefs, and discriminatory policies and practices. They lack access to basic rights like education, access to health, access to public places, play and so on. Very often prevailing attitudes perceive the life of a disabled child as being of less worth, less importance and less potential than other lives [32-33]. This situation may be further complicated by family and community attitudes and behaviour during the critical years when the children's personalities and self-images are developing [2]. Discrimination faced by disabled children continues due to the fact that few Governments have made a study of the causes and forms of such practices. With respect to causes, traditional attitudes lead to feelings of shame, superstitious fear and rejection in children with disability.

When compared with their non-disabled peers, children with disability encounter lack of equal opportunities, which impedes them from attaining their innate potential. Further, certain disabilities such as mental disability carry even greater stigma. If the child with disability happens to be a girl then the discrimination is doubled [34-35]. Lansdown [36] found that despite the explicit inclusion of disability as a ground for protection against discrimination in the UNCRC, 1989, and the provisions of article 23, which specifically addresses the situation of disabled children, the reality of disabled children remains largely unchanged in most countries of the world.

Tuli, [37] the ex-commissioner for disability states that a

majority of children with disabilities are from rural and low-income homes, where immunization coverage is poor, malnutrition is widespread and maternal health is severely undermined by frequent childbirth. She further argues that the pervasive tendency to underestimate the potential of children with disability leads to lack of recognition of their rights and hence their fulfillment.

According to the National Sample Survey Organization [38], 55 per cent persons with disabilities were illiterate and until recently, disabled children have been excluded from the national education systems. Children with disabilities are 4 to 5 times less likely to be enrolled in school. If they remain in school, they rarely progress beyond primary levels. The main barrier they face is lack of access to school including lack of specialized teachers for both physically and mentally challenged children, absence of teacher training programmes, absence of disabled-friendly infrastructure, including ramps, special chairs and toilet facilities as well as the mockery of adults and other children. This is corroborated by World Bank report [39] which states that at least one in 12 households includes a member with disability. Children with disability are five times more likely to be out of school than Scheduled Caste or Scheduled Tribe (SC/ST) children, and if they stay in school they rarely progress beyond the primary level, leading ultimately to lower employment and incomes.

In the Integrated Child Development Scheme (ICDS, 1975) [40], although it may have been the intention of the government to include disabled children in the term 'all' children, there is a gap between policy stated and policy enacted, as the ICDS does not include them, in practice. Due to ill-defined policy objectives during the policy formulation stage, policy remains silent on the issue, not clarifying that 'all' means disabled children as well. Implementation strategies for the inclusion of these children therefore are not worked out, which leads to non-inclusion of disabled children from the programme [41].

According to major reports as well as the World Bank Report of 2007 [39], done together with the Ministry of Social Justice and Empowerment (GOI), although the Sarva Shiksha Abhiyan (SSA), flagship programme of government of India on Universal Education for All, has made a concerted effort to promote the inclusion of children with special needs to some extent, the system faces challenges in identifying these children and responding to their needs. Only around 1 per cent of funds under the SSA are spent on inclusive education. The budget for educating children with mild to moderate disability in regular school settings has not increased commensurately since the focus on inclusive education began in the 1970s [39].

The Right to Education Act, 2009 has advocated the right of children to free and compulsory education up to the age of 14 years. The Act incorporates a section on disadvantaged children which also includes children with disability. While the Act mentions about the inclusion of children with disability in the educational system, it does not provide mechanisms for implementing the same. The study conducted by Save the Children [42], states that a tandem has

developed between an acute lack of services for disabled children, attitudinal blocks of the larger society, lack of information among parents as well as service providers, and the missing convergence between various agencies.

Parents know their children best and the best for their children. Their action often takes the best interest of the child and is usually directed towards evolving capacities of the child. Parents represent the child and have to claim his/her rights. Raising a child poses considerable responsibilities for any parent. The business of caring for and nurturing a young and helpless human being, instilling values, teaching skills, and finally allowing the child to gradually prepare to be independent and self-sufficient, is life's most complex and challenging tasks. The parent of a child with disability retains all of these responsibilities in addition to the task of bringing the child to a certain level of societal expectations, whatever the nature of disability. Parents can assist in making sure their children understand the services available to them and avail of the same. Thus they are the respondents in the study.

The UNCRC, 1989 and the World Summit on Children 1990 have influenced to some extent India's policy of children. This led to the formulation of a National Plan of Action for Children in 1992 which calls for government departments, community and society at large for greater participation for the welfare and development of children with disabilities. Provisions to integrate children with disability have been made in District Primary Education Programme (DPEP) since 1998. The National Plan of Action for Children (2005) has recognized children with disability as a special category to be provided with special conditions for their development.

For the first time in the history of independent India, a separate law, Persons with Disability Act, 1995 had been formulated which mentions about the multiple needs of disabled people. It holds the State responsible for the education of all disabled persons until the age of eighteen, and stipulates 3 per cent reservation for them in government educational institutions or institutions supported by the government. Government schools are bound by law to provide admission to disabled students. The law also stipulates that all public buildings, including educational institutions, be made accessible to everyone. Also since India ratified the Convention on the Rights of People with Disabilities (2006) in October 2007, an impetus for amending the Persons with Disability Act came from the government and is under a review presently and a bill is being proposed. The CRPD has ushered in a new paradigm of disability rights. The social model of disability, concept of universal design, legal capacity with support and no forced interventions are critical components of this new paradigm. The proposed bill recognizes all three features of the new paradigm in its text and makes a commitment to make them the driving force of disability rights.

Rights of Children

A human rights perspective in disability means viewing

children with disability as subjects and not objects. It entails a shift from viewing this group of children as problems towards viewing them as holder of rights. It means locating problems outside the disabled children and addressing the manner in which various economic and social processes accommodate the difference of disability. It means including children with disabilities in all social, political and economic processes in the manner any other citizen of the country might be expected to – and this process is termed as 'Inclusion'. All children are entitled to rights listed in the UNCRC (1989), and so are the children with disability. The special rights for children with disability in article 23, ensures that children with disability are entitled to the help they need in order to access their other rights. It also states that children with disability are to be provided with all possible conditions and support that will enable their holistic growth and development. Does it really happen so in practice?

Lansdown [43] states that, as minors by law, children do not have the autonomy or the right to make decisions on their own for themselves in any known jurisdiction of the world. Instead their adult caregivers, including parents, teachers, social workers and others are vested with that authority depending upon the circumstances. This state of affairs gives children insufficient control over their lives and causes them to be vulnerable.

The General Comment of the Committee on the Rights of the Child [33] discussed that social discrimination and stigmatization lead to the marginalization and exclusion of children with disability, and may even threaten their survival and development if it goes as far as physical or mental violence against children with disabilities. Discrimination in service provision excludes them from education and denies them access to quality health and social services. The lack of appropriate education and vocational training discriminates against them by denying them job opportunities in the future. Social stigma, fears, overprotection, negative attitudes, misbeliefs and prevailing prejudices against children with disabilities remain strong in many communities and lead to the marginalization and alienation of children with disabilities.

According to UNICEF [44], in spite of almost universal ratification of the UNCRC, and the social and political mobilization that led to the adoption of the Convention on the Right of Persons with Disability, disabled children and their families continue to be confronted with daily challenges that compromise the enjoyment of their rights. Discrimination and exclusion related to disabilities occur in all countries, in all sectors of society, and across all economic, political, religious and cultural settings.

A look at some articles of the UNCRC which are relevant to children with disability will build the context in which this study is located. If we start by looking at how Article 23 is implemented which is about recognizing disabled children as full human beings. This recognizes disabled children's right to: enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active

participation in the community. Disabled children also have the human right to assistance provided in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development. The paragraph 2 and 3 of the article 23 stress on the fact that disabled children are entitled to special care and the special needs of the disabled child must be met through provisions which shall be made available through enabling access of the disabled children to the same through special efforts. However, the needs of disabled children for education, shelter, protection, food and love are not 'special' but the same as those of other children. By focusing on 'special needs', of the disabled children and reiterating the entitlements to special provisions the article 23 reinforces the medical model of disability. In other words, the focus of the language used in the text is on the deficiency of the child with disability and hence the provision of special services to fill the deficiency. However, many of the difficulties faced by children with disability are created by a hostile environment which creates barriers for them in myriad ways – denying access to buildings and public places, excluding them from public transport, failing to provide information in a manner accessible by them, making inappropriate assumptions about their competence and potential-- thereby reinforcing prejudice and discrimination.

Article 2 states that all the rights entitlements in the convention are applicable to all children without discrimination, including on grounds of disability. Segregated schooling experiences in special institutions, denial of admission to regular schools, or absence of educational experiences in rural areas for disabled children, exclusion from playing with all children on grounds of disability are examples of discrimination that disabled children face every day. Offering disabled children different or lesser education simply because of their disability is practicing discrimination and a breach of article 2.

Article 3 states that in all actions concerning children, their best interests must be a primary consideration. However, this claim needs to be subjected to a scrutiny of how segregated education serves to protect the child's rights. For instance does it offer the same opportunities as those available to other children? Does it remove them from home and exclude them from family life, social networks and opportunities for friendship? Does it result in social exclusion and lack of participation? Does it expose them to stigma and prejudice? Segregated education or special schools perpetuate differential opportunities to children with disability and those without disability, exclusion from homes, family life in cases where children are institutionalized, exclusion from social networks and opportunities for friendship, lack of participation and so on. Lansdown [36] correctly opines that the best interests of the child are likely to be promoted not by removing the child from mainstream school but rather by addressing the problems within the school.

Literature is replete with data and research on parents' reactions to the birth of child with disability, stress related to

caring for child with disability and stressors, the efforts they make in coping with stress, and some positive coping outcomes of rearing disabled children. However, there is dearth of information on the subject of information on parents' awareness of rights entitlements of the children with disability and their initiatives in securing entitlements of rights for the same children.

5. Methodology

This study lends itself to the use of a quantitative paradigm as the findings allow for generalization using a large sample size. It has adopted a combination of descriptive and exploratory research design. The data collected using a descriptive design tends to be more exact and precise than other causal designs [45], so this research design was considered appropriate for the study. According to Best and Kahn, [46] a descriptive study describes and interprets what is. The aim of the study was to describe the ground realities, as they are existing, vis a vis parents' awareness of the human rights entitlements of their children with disability.

Parents of children with disabilities are the target audience who would benefit by the findings of this research. Parents who participated in this study were mostly from low middle income group to low income group. Majority of them were mothers reflecting the ground reality of mothers being care providers of children with disabilities often giving up their careers. Their age varied from thirty five to fifty seven years. Most of them were from a nuclear family setup. Several of them had two children. Some of them were anxious and concerned about the future of their children.

As mentioned earlier, UNCRC (1989) was used as the basic document for looking into the specific rights entitlements of children with disability. Children's rights as per the UNCRC (1989) are human rights of children with particular attention to the rights of special protection and care afforded to the young. These include their right to identity; to grow up in a family with both parents, right to protection as well as access to food, health care, education, opportunities for development and right not be discriminated against. The interview schedule focused on above mentioned entitlements of children with disabilities for collecting information from parents. Each parent's responses were assigned scores that were added up to arrive at total score that reflected that parent's level of awareness. Awareness score denotes the level of awareness of the parent with respect to their child's human rights entitlements. A comparative analysis of parent's awareness scores was made on different personal and socio-economic variables since this research also pre supposed that awareness of parents about rights of children with disabilities is impacted by (i) personal factors of parent (i.e. age, sex, religion, educational attainment, occupation) (ii) socio-economic factors such as number of children and nature of family, family income, per capita income) and (iii) factors relating to child with disability (i.e. age, sex, type of disability, age at the onset of

disability and birth order of child in the family).

Impact of above mentioned factors on average awareness levels of parents were also studied. Another component of the research was to find out if parents had taken any steps to secure any entitlements of rights that have been hitherto unavailable to the children. Focus group discussions were conducted for this purpose which was the exploratory component of the research study.

Descriptive and inferential analytical procedures have been applied to the data after its processing. The inferential analytical procedures applied to the data are t- test, F-test, and classification tree. The findings are collated with the scenario at ground reality level. The generalization thus gained provided an insight into understanding parents of children living with disability and their awareness of human rights entitlements for their children.

Parents as Respondents

Parents' responsibilities towards their children range from, registering the birth of a child with a disability; providing equality of care between all children in the family including children with disabilities; respecting the evolving capacities of a child with a disability to take a growing level of responsibility for decisions affecting her/him; ensuring that where a school place is available, the child is enabled and encouraged to go; providing support to children with disabilities in their education, for example, by learning sign language to facilitate communication, attending school meetings, helping with homework; where a school place is not available, advocating for the child's right to education – holding schools and education authorities accountable in fulfilling their obligations to children with disabilities in their education; ensuring that children with disabilities are provided with the same quality of access to food, water and shelter as other children in the family; ensuring that, to the maximum extent possible, children with disabilities are able to access the healthcare they require; challenging prejudice and discrimination within the local community; inclusion of children with disabilities in all social and cultural events on an equal basis with all other children; facilitating opportunities for children with disabilities to play and associate with other children.

Therefore parents are the primary duty bearers. They play a dual role in the life of child with disability. One as primary stakeholders to make provisions for their child's growth and development and the other as advocates seeking from the rest of the duty bearers (i.e. social structures and institutions, non-governmental organizations and the government at the local, state and central level) services and provisions required by their children with disability, both as required by other children i.e. those without disability and the special requirements on account of their disabilities to bring them at par with children who are not disabled.

Another reason for focusing on parents is the fact that children with disability are, more than other children, dependent on their parents for their basic as well as higher order needs. Also, parent's awareness and efforts to access

rights for their children will inevitably and ultimately lead to awareness growing among children themselves. Interventions by governmental and non-governmental organizations for parents do not include human rights component and therefore it becomes even more important to understand parental awareness and understanding of human rights.

Study Objectives

The research study aimed to find out the extent of awareness parents have of human rights entitlements that their children with disability have within the Indian context. 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. Therefore this research study attempted to find out the ground realities in terms of awareness that parents of children with disabilities have of human rights, which their children are entitled to; whether these rights are accessible to their children; and have any of them taken any initiatives to secure these rights for their children.

Study Area

The geographical location of the study was Mumbai which is the most populous city in India and fifth populous city in the world. It is the financial, commercial and entertainment capital of India, generating 6.16 per cent of GDP and accounting for 25 per cent of industrial output, 70 per cent of maritime trade in India and 70 per cent of capital transactions to India's economy [47]. Its potential to offer a higher standard of living attracts migrants from different parts of the country and in turn makes the city a unique blend of many cultures and communities. Being a major financial centre, people from all over the world come here for business. The presence of Bollywood, television production houses, print and media and music companies draw a large number of people who want to make a name for themselves in the entertainment industry from different parts of the country to Mumbai. The city also has several educational institutes of repute offering professional education. All these characteristics make Mumbai a metropolis populated with people from various walks of life, touching a population of approximately 18 million [48]. Hence, Mumbai 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.

Sampling

The universe consisted of all parents of children between 6 to 14 years of age with disability (with visual impairment, hearing impairment, orthopedic impairment and mental retardation) availing of services provided by the

governmental or non-governmental special schools and organizations for disabled children in the metropolis of Mumbai.

The research has used stratified random sampling design. Stratified Random Sampling is a method of selecting a sample of ' n_i ' units out of ' N_i ' units from the i^{th} strata of population [49]. The sample of parents was drawn using two-stage stratified random sampling technique. First, city of Mumbai is divided into five strata (or zones), then from each strata first stage units (i.e. organizations/special schools) are selected so as to cover the categories of disabilities (i.e. Visual Impairment, Hearing Impairment, Orthopaedic Handicap and Mental Retardation). The parents (i.e. second stage unit) are selected in a random manner from each selected school in each stratum so that sample is representative of population of parents of children with disability in Mumbai. From the roster provided by special schools/organizations, parents who agreed to be interviewed were taken as respondents. Sample of 335 parents of children with disability were selected.

Tools for Data Collection

Tools used for data collection included an interview schedule for parents, a focus group discussion (FGD) guide for parents and diary notes maintained during data collection. Through the interview schedule an effort has been made to study and describe the current situation as it exists with respect to parents' awareness on rights entitlements, its relationship with personal, socio-economic and child related factors and efforts made by parents to seek entitlements of their children.

A small component of the study was of qualitative nature corresponding to the objective of finding out from parents if any of them had taken steps to secure rights entitlements that are not yet available to children with disability. Focus Group Discussions were used for this purpose. A diary of notes and significant observations was maintained throughout the data collection process. The observations so recorded have been weaved in the paper.

Interview Schedule for Parents

The interview schedule covered questions which had been framed in a manner so as to reveal whether rights entitlements had been fulfilled for children with disability within their circumstances. The questions fulfilled the objective to find out parents views on the status of child with disability, in terms of life situations and circumstances, whether they were aware of a particular service, benefit available to their children. Some questions also aimed to find out parents views about children with disability in general as well.

The interview schedule was divided in three parts. The first part sought information on demographic details of the respondents which included personal information on parents, family profile attributes of the child with disability. Personal information on parents included factors like their age, gender, religion, educational attainment, occupation, number of

children. The family profile looked at factors like the nature of family (nuclear, joint or extended family) number of family members, and income per month. The attributes of the child with disability included their age, gender, and kind of disability faced by them, age at which disability appeared, and child's chronological rank or birth order in the family. Impact of each of these factors on awareness of parents was analyzed and the analysis is presented in next part of the paper. The other two parts of the interview schedule had questions corresponding to objectives one and two for the research study.

Respondents were assigned awareness score on the response given by him/her on each question asked in part one and two of the interview schedule. The rating of scores has been done in a manner, that higher the parent's awareness, higher was the score awarded to them, which ranged from 2 to 0. The awareness score of each question was added to calculate the overall awareness score for parents' on the basis of their responses. The minimum awareness score that a parent could be awarded was twenty eight and the maximum awareness score that any parent could be awarded was eighty three.

Focus Group Discussion Guide

The Focus Group Discussion Guide explored the initiatives which parents had taken to secure rights of their children with disability, which hitherto has not been available (to the children with disability). For this five focus group discussions (FGD) were conducted with parents availing of services in organizations/schools. Parents knew each other as they happened to meet naturally when they visited the organization /special school with their child. The FGDs were planned at place and time which was convenient to parents. Each group had 10 to 12 parents. In all the focus group discussions had included 60 parents.

The group consisted of mothers and/or fathers of children with disability. They were from varied backgrounds. Parents had different educational and occupational status. They were from all age groups and economic status.

Data Collection

Permission for data collection was sought from two sources, namely the special school/organization authorities and the respondents. The data was collected on the premises of the special school/organization after seeking prior permission from the head of the institution. The date and time for the same were fixed in advance. On the designated day, a quiet space was arranged within the special school/organization, where interviews were conducted without disturbance. The organization/ special school provided the researcher with the roster of parents' names. Parents visiting the Special school/ organization on that day were requested for their time and permission for the interview. Once these were secured, the researcher explained the purpose for conducting the interview. The interviews were conducted in Hindi and English depending on parent's preference of language. Parents had showed concern about

the issue of confidentiality which was assured to them by the researcher. The duration for each interview was between an hour and hour and half. The same procedure was followed for conducting focus group discussions. The time taken for collection of information was one year and four months.

Data Analysis and Statistical Tools

The inferential analysis of impact of factors on parents awareness average scores has been carried out at three levels viz. univariate analysis studying impact of single factor (using t-test and F-test), bivariate analysis (cross effect of educational attainment and gender) and multivariate analysis (using classification/decision tree method). Descriptive analysis consisted of collating and presenting the parents responses to each of the questions in the interview schedule. A summary of findings is discussed in the next section of this paper.

Awareness score denotes the level of awareness of the parent with respect to their child's human rights entitlements. Awareness scores were calculated to arrive at a picture, which in one glance would show the level of awareness of parents about human rights entitlements of their disabled children. These awareness scores for each parent were plotted on a graph between 0 and 1, with parents listed on the X-axis and respective awareness score of each parent on Y-axis, to arrive at a scale of awareness scores.

To study the impact of personal factors (parents' age, sex, religion, educational attainment, and occupation), socio-economic factors (number of children, nature of family, income level of a family, and per capita income), and factors related to the child with disability (child's age, child's sex, child's type of disability, child's age at the onset of disability, child's birth order), on the awareness level of parents, the awareness scores of all parents with respect to each factor were averaged. Its impact was studied so as to make a comparative analysis of parent's awareness on different personal and socio-economic factors and enable a smooth analysis of quantitative data. Further, an attempt was made to identify the factors which significantly affect the awareness level of the parents with respect to the rights of the disabled child.

An F-test is carried out on the awareness scores of parents with respect to factors mentioned above, to test the equality of variance in their values. So, in case the value of F-test calculated is less than the value of F-test tabulated, then the conclusion is that there is equality in variance. When the value of F-test calculated is more than the value of F-test tabulated the variance in awareness scores is unequal. F-test preceded the t-test in the factors where graphs showed difference in awareness scores of parents belonging to different categories for studying variance of a particular/specific factor.

In order to identify statistically significant factors, a statistical t-test is used to test the hypothesis of "No Difference in the Mean Awareness Scores" of Parent having different age, educational attainment and the rest of the factors mentioned earlier. Significant value of t-test indicates

that a particular individual factor is significant/ dominant in affecting the awareness level of a parent.

In addition to the t-test there was a requirement to find out if there was a group of factors together (rather than individually) was making a significant impact on parents awareness level from among fourteen factors mentioned above, decision tree method is used, with the help of SPSS Software package .

Awareness Scale of Respondents

To find out whether a parent is highly aware or poorly aware regarding human rights entitlements of their children with disability, and to present the spectrum of awareness levels of parents, the individual awareness scores of each parent were plotted on a graph and developed into an awareness scale. The awareness scores for each parent were plotted between 0 and 1, with parents listed on the X-axis and respective awareness score of each parent on Y-axis, to arrive at a scale of awareness scores.

This was considered necessary because calculation of awareness scores of parents in absolute terms only presents a picture of awareness level of each parent whereas the awareness scale provides in one glance a comparison of parents awareness levels vis a vis each other. Also the awareness scale could be developed and used in myriad ways to make a comparative study of various facets of awareness with respect to disability among different stakeholders and with numerous perspectives. Research in social work becomes more pertinent to interventions if the findings can be used practically in the field.

In order to work out each parent's position on the

'Awareness Scale', the awareness score has been scaled using the following procedure:

Awareness Scale = {[Actual Awareness Score of Respondent – Minimum Awareness Score Possible]/ [Maximum Awareness Score Possible – Minimum Awareness Score Possible]}

According to the interview schedule the maximum and minimum awareness scores that parents can get are as follows:

Maximum Awareness Score Possible = 83 as worked out from Interview Schedule

Minimum Awareness Score Possible = 28 as worked out from Interview Schedule

Based on the above formula, each respondent parent's position on the awareness scale is calculated and plotted on scale of (0, 1) on y-axis and parent on x-axis wherein '0' represents the Lowest value and '1' represent the Highest awareness that a parent can have. The graph depicting the range of parents' awareness through awareness scale is presented on the next page.

6. Results and Discussion

This section includes a discussion of results obtained by analyzing parents' responses to the questions on the interview schedule. A summary of the same is presented in the first sub-section. The second sub-section discusses the impact of various factors considered in the study on parents' awareness levels.

Figure 1. Graph Plotting of Respondent Parent on the Awareness Scale

Awareness of Parents on Rights Entitlements of children with Disability

Through descriptive analysis and the focus group discussions conducted in the five organizations/ special schools it was clear that all parents knew that children have rights entitlements. However when parents were asked to list rights of children they could list only right to education, employment and right to parental property. They could not list any other rights. The researcher listed some of the rights mentioned in the UNCRC, like right to life, right to name and nationality, right to development including education, health and play, recreation, rest etc, right to vocational training. Parents voiced that these rights are mandatory for all children but few only have access to these rights. They added that the rights for disabled children were neither acknowledged nor accorded by the society. They expressed their disappointment with society for creating discriminatory experiences for their children. A high percentage (45 per cent) of parents and their children with disability reported experiences of discrimination. Another fact to be revealed was that parents view their children, both disabled and non-disabled as equals and do not discriminate. Also right to identity, citizenship and nationality has been fulfilled for 97 percent of children with disability in the sample. It was heartening to note that the right to be with parents and growing up in a family was being realized for 93 percent of children with disability and the disabled child is playing with other children in their neighbourhood.

Parents believed that providing education and or vocational training was their hope for future economic independence of their children which would result in securing of rights for their children. However, 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. All parents also agreed that the possession of disability certificate for their disabled child enabled them to seek benefits from government policies and schemes and thus all had acquired the same. Some had experienced hostility from the service providers when they had sought special privileges mandated by the government on behalf of their children with disability. The parents mentioned that public infrastructure is organized so as to meet the needs of individuals without disability. Some of them were disappointed by the fact that travelling long distances with children who had orthopedic impairments or mental retardation was a struggle due to lack of supportive infrastructure.

Most of the parents knew from their experience that they cannot depend on others for support while bringing up their disabled children and hence they did not expect any help, support or assistance from any quarter. A very small section of parents (i.e. 7 percent) felt that they themselves, family, community and government are jointly responsible for development of children with disability. These parents probably had a healthy self-esteem and had not allowed any sense of guilt to develop within them for having a child with

disability. These parents had also given some thought on the role played by self, family, community and government in providing for situations that would lead to fulfillment of a need leading to growth and development of children 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 had not occurred to any parent.

With respect to disabled child's right to participation, it was found that parents believed in their disabled child's evolving capacity and, it was a good trend that 34 percent parents sought their children's views on matters directly affecting them. Parents do contemplate at times on the impact of their decisions on the child but including them in discussions while making family decisions is not a common feature of Indian families, which was corroborated by the data.

Parents who had made efforts to seek inclusive education for their children with disability experienced barriers of discrimination, stigma and non-cooperation from school staff. A few shared their experiences of efforts they had made towards inclusion of their disabled children in mainstream/regular school as they were aware of 3 per cent reservation in mainstream schools for children with disabilities. Their children had initially been accepted in inclusive set-ups, but after a year or two they were asked to take their children to special school. The reasons they were given varied from children with disability not being able to maintain the same pace as their peers, slowing down the pace of learning for the entire class, parents of other children objecting to the presence of a child with disability in their child's class. They had had to remove their child from mainstream school and send him/her to regular school. Other than that no effort had been or steps taken to secure rights of children with disability. None of the parents knew any other parent who had taken some concrete steps to secure rights entitlements of their children with disability. Overall a sense of helplessness in being able to seek rights entitlements for their children with disability could be sensed.

Impact of Factors on Parents Awareness

Univariate analysis of factors was carried out through t-test in case there were two variables of any factor and F-test had been applied in case of factors having more than two variables. Therefore, t-test was applied when examining the impact of gender of parent and child with disability on awareness level of parents on the rights entitlements. In both cases gender did not have any significant impact on the awareness levels of parents. For rest of the factors F-test was applied since there were multiple variables.

From the F-test what came to light was that although

parents' educational level has a positive relationship with the awareness scores (which means that higher the level of educational attainment, higher was the parents' awareness score), educational attainment of parents is not statistically significant. The type of child's disability was another factor which came up indicating significant importance as far as having an impact on the awareness of the parent is concerned. Another factor which was been found to be of significance was the birth order of the child with disability, where parents of disabled children who are youngest have higher awareness scores than parents whose first child was disabled. Similarly, number of children in the family was also found to have some impact of awareness level of the respondent parents with child with disability, parents having two children are more aware as compared with other parents, which could be on account of their maturity level as well. Further parents having more than three children are found to be least aware. However, F-test for all the above factors revealed that these factors were not statistically significant.

In order to further substantiate the findings, a decision tree method was used to establish the dominant factors from among the all the personal and socio-economic factors of respondent parents which impact the awareness level of parents of child with disability. From the decision tree method, it was established that parents' education attainment is the most dominant factor affecting awareness level of respondents. In addition to this, from the remaining factors, birth order of the child in the family, child's type of disability and number of children in the family were also dominant factors affecting awareness of respondent parent on rights of child with disability. From this finding it can be surmised that these factors individually were not significant, but in

combination with other factors they became significant which is further corroborated by the results of the decision tree method given below.

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

The cross effect of gender and education level of the parents, showed that fathers were generally found to have higher variability in the awareness score. However, mean awareness score of mothers was found to be higher than fathers.

This finding corresponded with the fact that seventy eight per cent of the sample was mothers indicating the bias in the sample of parents selected. However, this is clearly in tune with ground reality that exists, wherein mothers are largely expected to be present and taking more responsibility for the care and rearing of children in Indian society. Similarly the sample showed that even in the case of disabled children, mothers take more responsibility of the child than the fathers. Research has shown that patterns of care for disabled children reflect women tending to assume primary responsibility [50-51]. The ongoing day to day care, particularly intimate personal care, most often is undertaken by mothers. As the data clearly indicates mothers also play a key role in mediating between the disabled child and the health care as well as social system. Eventually mothers' complete involvement with the disabled child and interactions with various kinds of professionals or other people leads to higher levels of awareness being built in them. The graph presented below depicts higher awareness of mothers for any level of educational attainment and higher variability in awareness scores of fathers.

Figure 2. Graph of Awareness Score of Respondents: Gender-wise and Education Level-wise

7. Conclusions

Parents of children with disabilities, face challenges that are the same as those of all parents. Their needs are also same as other parents. Nevertheless their awareness on rights entitlements of their children with disability is impacted by their response to the existence of disability in their child. Majority of the parents interviewed had accepted their child's disability. They made attempts to provide best facilities for growth and development of their child that they could within the circumstances and resources that were available to them. They were hopeful about improvement in their child's condition. Their concern was for the future of their child in terms of whether their child would be economically and physically independent, and they worried about who will take care of their child after their death. The concern of the research study was whether parents have looked at disability in their child leading to segregation in education from the mainstream education, discrimination in society and marginalizing experiences for the child. All these result in human rights violations of children with disability, but had parents really understood these disabling experiences as human rights issues.

The findings revealed that none of the parents had viewed the experiences of discrimination faced by their children as human rights violations. Not a single parent mentioned that the government must make certain provisions in terms of social and physical infrastructure that should be available for inclusion of children with disability in social and community life; or attitudes of people towards children with disability should be of acceptance and tolerance for differences, non-discriminating and non-stigmatizing. Parents believed themselves to be responsible for the condition of their child and have neither questioned nor challenged the prejudices and biases of the society.

Unless disabled children's specific requirements are recognized in ways which enable them to be included, and have equal access to the things that their nondisabled peers take for granted, they will continue to be denied access to their human rights. Lack of awareness among parents, families, concerned institutions and service providers' (the decision makers, government, and law enforcers) means that unless they are specifically mentioned, children with disability become marginalized within the general children's agenda. Girls with impairments suffer still further discrimination – they are more likely to be abandoned, discriminated against, and excluded from education, marriage and motherhood.

Since India ratified the UNCRC, the experiences of disabled children have largely remained unrecognized. Among the people with disability in India thirty per cent of them are children below the age of fourteen years [48]. At the policy level, progressive legislation, schemes and provisions exist for them. But at the ground level, the disabled children continue to be neglected and marginalized, with the onus of care on the family rather than the community. Even today, data related to disability among adults and children varies

from one source to another. Lack of reliable figures regarding children living with disabilities and the different types of disabilities they face has been an obstacle in planning and making adequate interventions [35]. This illustrates the insignificance accorded to the lives of the disabled children. However, there is a need to acknowledge them as individuals in their own right and rights based approach is required to ensure that children with disability are able to realize their potential.

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