

SPECIAL NEEDS CHILDREN IN INSTITUTIONAL CARE- ISSUES AND CHALLENGES

HRISHIKA¹ AND SHRADDHA SHARMA²

ABSTRACT:

The PWD Act 1995 (The Persons with Disabilities) defines disability as Low vision, Blindness, Hearing impairment, Loco motor disability, Leprosy- cured, mental retardation and mental illness³. The Convention on the Rights of Person with Disabilities (2006) defines that a person with disability means who have long term impairments including physical, mental, intellectual or sensory which may hinder their full and effective participation in the society. The Juvenile Justice (Care and Protection of Children) Act, 2015 under Article 50 (2) states that the State Government shall designate any Children's Home as a home fit for children with special needs delivering specialised services, depending on requirement⁴. As per the standardized norms under JJ Act; the institutions provides the basic requirement of the children with special needs such as food, shelter, clothing, medical attention and other suitable aids but the major concern for these child care institutions (who are designated as adoption agencies by central government) is to find a suitable family for adoptable children with special needs and if adoption is not possible then to mainstream them. In such circumstances the future of the children with special needs is uncertain and highly questionable. The objectives of the proposed study are: (a) To identify the issues of children with special needs living in institutional care; (b) To address the challenges of child care institutions in mainstreaming children with special needs; (d) To assess the existing legal framework in India.

Keywords: Institutional care, Children with special need, Disability, Child care and Protection

I. INTRODUCTION

The PWD Act 1995 (The Persons with Disabilities) defines disability as Low vision, Blindness, Hearing impairment, Loco motor disability, Leprosy- cured, mental retardation and mental illness⁵.

¹ Hrishika is doctoral scholar at Amity Institute of Social Sciences, Noida, Uttar Pradesh

² Dr. Shraddha Sharma, Assistant Professor, Amity Institute of Social Sciences, Noida, Uttar Pradesh

³ The Persons With Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995

⁴ The Juvenile Justice (Care and Protection of children) Amendment Act 2015

⁵ The Persons With Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995

Children with special needs or children with disabilities are persons below the age of 18 years who have long term mental, physical or intellectual impairments which hamper their effective participation in society⁶. According to the 2001 Census report, amongst all persons living with disabilities, 35.9% were children and young adults in the 0-19 age group. Three out of five children in the age group of 0-9 years have been reported to be visually impaired.

India's population of abandoned and destitute children is estimated to be 20 million⁷. However there is no authentic and reliable data available on the number of cases of abandoned children having disability and are residing in institutional care. Institutional care is considered as the best means to provide care and protection to children who are in need of care and protection. Among the population of children living in institutional care there are children with special needs/ disability, who are at high risks due to being surrendered or abandoned by the biological parents and due to their severe health conditions. A significant number of children affected by HIV/AIDS and substance abuse, as well as mentally or physically challenged children are in need of long term care because of abandonment, death of one or both parents to care for them; such children are especially vulnerable as they are least likely to have family care alternatives and hence require specialized institutional care and treatment including medical, nutritional and psychological support⁸. As per the standardized norms under JJ Act; the institutions provides the basic requirement of the children with disability/ special needs such as food, shelter, clothing, medical attention and other suitable aids. The Juvenile Justice Act lays down minimum standards on infrastructure and quality of care for each child care institution, but often these are not adhered to and issues such as overcrowding, lack of hygiene and dysfunctional infrastructure are widespread⁹.

The major concern for child care institutions is to mainstream children with disability/ special needs. The child care institutions encounter challenges in working with children with special needs/ disability due to lack of resources and financial aids. Also there is lack of trained professionals and caregivers which may have adverse and negative effect on the children with special needs. In such scenario the future of children with special needs/ disability is highly questionable.

⁶ The convention on the Rights of Person with Disabilities 2006

⁷ Report on 2nd biennial conference on Improving standard of care for alternative child and Youth care: Systems, Policies and Practises

⁸ Database on Child Care Institutions registered under Juvenile Justice (Care and Protection of Children) Act 2000 (as amended in 2006). National Institute of Public Cooperation and Child Development.

⁹ Study on Child Abuse: India 2007. Ministry of Women and Child Development. Government of India.

II. OBJECTIVES

Present research paper aims to address the situation of children with special needs/ disability in India. The objectives of the research study are:

- (a) To identify the issues of children with special needs living in institutional care;
- (b) To address the challenges of child care institutions in mainstreaming children with special needs;
- (c) To assess the existing legal framework in India.

III. METHODOLOGY

The present research paper is an attempt to analytically examine the situation of children with disability/ special needs in India. The researcher has adopted descriptive research design. The present study is based on secondary sources: international and national publications, official publication of central and state government, journals, research studies, news paper and scholarly articles for the collection of the data. The results of the study are gathered from comprehensive literature survey.

IV. LEGISLATIONS FOR CHILDREN WITH DISABILITY/ SPECIAL NEEDS IN INDIA

India being a democratic country imbued to secure all its citizens rights (including children with disability/ special needs) to equality, freedom and to live with dignity without any discrimination on grounds of age, color, sex, race etc. Indian government has made several provisions/ laws to safeguard the rights of the marginalized groups of the society.

Indian constitution guarantees fundamental rights to its citizens including children with disability. Under the Article 14 of the constitution every citizen of the country is equal before law. Article 15 and 16 of the constitution designate States to make special laws and provisions for the betterment of any backward group of the society and all kind of discrimination on is prohibited. Indian constitution guarantees right to education to all citizens including the disabled and in Article 29 (2) states that no person/ citizen shall be denied admission into any educational institution maintained by the state or receiving grant from state funds. Article 45 of the Constitution directs States to provide free and compulsory education for all children (including the disabled) till the age of 14 years.

The Persons With Disabilities Act, 1995¹⁰ came into existence on 7th February 1996. The PWD act was enacted with the objectives of Promoting and ensuring equality and full participation of persons with disabilities and Protecting and promoting their economic and social rights. The main provisions provided under the PWD Act are- to prevent and early detect, provide education, opportunities of employment, non-discrimination/barrier free access for persons with severe disabilities and social security. The PWD act states that government shall screen periodically all the children with disability to identify the ‘at risk’ cases. The PWD act also provides several provisions to ensure education for all.

The Mental Health Act, 1987¹¹ regulates standards in mental health institutions. The act was made with the main objective to regulate admission process of mentally ill person in hospitals for psychiatric assessment. The Act is made to protect the rights of mentally ill person who do not have proper knowledge and understanding to seek treatment voluntarily. There is a provision for admission of mentally ill person on request of parent/ guardian. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999 was enacted to fulfill the needs of the families who seek reliable arrangements for their severely disabled children. The main objective of this act is to enable and empower person with disability to live without any barrier in society¹².

V. PERCEPTION AMONG PARENTS OF SPECIAL NEEDS/ DISABLE CHILDREN

Family holds the primary responsibility of the child. The process of including a special need child in society as a whole begins with the access to everyday experiences in his/her home with parents and primary caregiver who plays a central role¹³. Every parent expects a mentally and physically healthy child but when a child with disability/ special needs born or the child become disable accidently or due to any other reason; the parents of such child starts experiencing a burden. This is mainly because of the social stigma attached with disability. Parents of special needs/ disable generally show a negative perception towards the disability of their child. There are ample number of researches which found the negative experiences and feelings of the parents. The studies reveal that the parents/ siblings/ families of children with disability/ special needs experiences shame, guilt and high level of stress. Some parents who have special needs children experience helplessness, anger, guilt, depression and self blaming. It is found that the siblings also experience feelings of shame and embarrassment¹⁴.

¹⁰ PWD Act, 1995. The Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Act 1995. Published in Part II, Section 1 of the Gazette of India.

¹¹ The Mental Health Act 1987

¹² The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.

¹³ United Nations Educational, Scientific and Cultural Organization, *Open File on Inclusive Education*, op. cit.

¹⁴ Frude N. *Understanding Family Problems: A Psychological Approach*. Chichester: John Wiley, 1992.

Other stress is also created due to marital conflicts associated with rearing the handicapped child, extra financial burdens to obtain the necessary services, and fatigue and loss of leisure time due to care-taking responsibilities¹⁵. This stress and negative approach when not dealt properly at the early stage may encourage parents to abandon their special need/ disable child. Disability of the child is one of the reasons of child abandonment because the family finds incapable of rearing a disable or special need child. Bharti Mehindru (1988) found that there are so many factors responsible for the abandonment of children which includes poverty, alcoholism of father, large family size, step parents, sexually victimized child, and death of one or more parents, abnormal children, diseased parents and insecure environment. Children with disability/ special needs are at high risk as they are dependent on adults for their needs and when adults particularly parents don't accept them and holds a negative approach towards them it makes them more vulnerable.

VI. ISSUES OF CHILDREN WITH DISABILITY/ SPECIAL NEEDS

Right from the difficulties in performing day to day normal activities such as eating, bathing, going to toilet, walking, changing clothes, playing with other kids, accessibility to public places etc. children with disability/ special needs face other problems also. The major issue is social un-acceptance towards people with disability. In our society disability is considered as a curse and it is believed that disability is a result of one's bad deeds or karmas which create a social distance and people with disability are treated as people from a different world. Children with disability/ special needs are at high risk as they are dependent on adults for their needs and when adults don't accept them and keeps a negative approach towards them it makes them more vulnerable.

Another big challenge is education that children with special needs/ disability encounters because of lack of availability of special schools. Also very few initiative have been taken to promote education of children with disability in mainstream educational institutions. There are many issues that educational institutions are facing and as a result children with special needs/ disability come across challenges in attaining education which creates hurdle in the process of mainstreaming them. These issues are lack of learning material, lack of financial resources, unavailability of trained professionals/ educators/ teachers in dealing with children and unavailability of medical equipments. Teachers who do not have special training doesn't aware of strategies and tools to deal with the challenges. The process of including a child with a disability in society as a whole begins with access to everyday experiences in the home setting, with parents and caregivers playing a central role¹⁶. According to the Sixth All India Educational Survey report, of the 6,461 town and cities, only 334 or 5.1 percent (5.1%) towns and

¹⁵ McAndrew I. Children with a Handicap and their Families. Child: Care, Health, and Development 1976; 2: 213-237.

¹⁶ United Nations Educational, Scientific and Cultural Organization, *Open File on Inclusive Education*, op. cit.

cities have the facility of special schools catering to severe disabilities. The data of the survey shows that of a total number of 586,465 villages in the country only 241 have facilities for special education for the disabled. This result indicates the gaps in the implementation of policies and programmes pertaining to children with special needs/ disability.

VII. CHALLENGES OF CHILD CARE INSTITUTIONS IN MAINSTREAMING CHILDREN WITH DISABILITY/ SPECIAL NEEDS

Central Adoption Resource Agency (CARA) an autonomous body of Ministry of Women and Child Development, Government of India has designated Specialised Adoption Agencies (SAAs) for placement of children in adoption. The major challenge before Specialised Adoption Agency (SAA) is to find a suitable Indian family for children with special needs/ disability as there are very few prospective adoptive parents who prefer and seems willing to adopt a child/ children with special needs/ disability therefore, Central Adoption Resource Agency (CARA) has taken special initiative to placement of differently able children in inter-country adoption and as a result from April, 2014 till December 2014; CARA has placed 271 children in inter-country adoption out of which 154 children have got special needs¹⁷. According to Adoption Regulations 2017, the fundamental principle of adoption is that the preference will be given to place the child in adoption with Indian citizens with due regard to placement of the child in adoption in his/ her socio-cultural environment (as far as possible) but the abovementioned data indicates that large number of children with special needs/ disability are placed in inter-country adoption as compare to non disabled children. Mostly, Indian couples who register for adoption prefer a mentally and physically fit child. The one of the main reasons for this choice is to avoid the social stigma attached with disability which has become a taboo among people. The other reason for not preferring a special child/ disable child is incapability of rearing the child due to demand of high cost/ expenses in the treatment of such child which may include regular physiotherapy or speech therapy, surgeries, cost of medicines etc.

Children who cannot be placed in adoption and have severe disabilities are admitted in child care institutions and they need careful attention. Child care institution needs trained caregivers/ professionals who can understand the developmental issues of children with special needs/ disability. Unfortunately there are no proper guidelines for the appointments of the staffs in child care institutions are followed. Also due to the lack of funds and resources child care institutions face difficulties.

¹⁷ Annual report 2014-15. Ministry of Women and Child Development.

According to “Mainstreaming disability in development: India Country Report, 2005”; India’s disability organisations (including organisations both for, and of, disabled people) are underperforming, neither effectively representing the needs of disabled people nor holding the state to account. Broadly, disability organisations are either co-opted or disengaged.

VIII. CONCLUSION AND SUGGESTIONS

In India mainstreaming children with disability/ special needs is a challenging assignment to accomplish. A number of laws have been implemented but still the problem exists. Without removing the social stigma attached with disabled people; mainstreaming children with disability/ special needs would be impracticable. There is need to help families who are facing difficulties in rearing their children with disability to prevent the cases of child abandonment and to protect the rights of the children with special needs/ disability. The government has made several laws and provisions to protect the rights of the marginalized people including children with disability/ special needs but it is revealed from various researches that the families of special needs are not aware of these services. Awareness campaigns through media should be undertaken to generate education on disability among people at grass root level. Keeping the fundamental principle of adoption that the preference should be given to place the child in adoption with Indian citizens with due regard to placement of the child in adoption in his/ her socio-cultural environment; adoption agencies should make efforts to counsel adoptive parents to encourage in-country adoptions. This would not be possible without removing the stigma attached with disability. Hence government, NGOs and other stakeholders should make necessary and effective measures to remove this barrier. Child care institutions needs to strengthen the quality of the services in terms of trained professionals and caregivers who can understand the developmental issues of children with special needs. Children with disability/special needs should have free access to necessary medical aids. Child care institutions should promote educational and learning opportunities to mainstream children with disability/ special needs.

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