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# Impact of being a Disabled Parent

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NAMITA<sup>1</sup>

## ABSTRACT

*This paper begins by exploring the changing horizons in disability law and child rights internationally as well as nationally. However, the main goal of this paper is to explore the impact of being raised by a disabled parent. It not only highlights the similarities but the lack of differences in the parenting method. Despite having the same legal rights as any other parent, parents with disabilities are often discriminated against when it comes to family law issues. Various case laws have established that you must prove one parent is 'unfit' before terminating custody or visitation rights, but in reality, parents with disabilities are often treated unfairly in family courts.*

*For the purposes of the qualitative research, I have interviewed 14 students currently pursuing graduation or post-graduation courses in University of Delhi. They are of the age group between 18 to 24 years. 7 of them have been brought up by at least one disabled parent. They have a good understanding of the impact it has had on them. Most of them have personally experienced discrimination and oppression at the hands of the family members or state authority. 7 of them have been brought up non disabled parents. Using their opinions and experiences, I have highlighted various lacunae present in implementation of rights of disabled parents and also provided some solutions as to overcome those.*

## I. INTRODUCTION

*“Children must be taught how to think, not what to think.”*

- **Margaret Mead, Cultural Anthropologist**

The adoption of the Human Rights Charter by UN in 1998 marked the beginning of focus of social rights. Hence, the latter half of the 17<sup>th</sup> century witnessed amalgamation of these three categories of rights, namely political, economic and social. India adopted the constitution of a new born state at a time when there was fusion of best of the values of the west and east which was reflected in comprehensive understanding of rights. However, certain categories of marginalized groups which include the disabled, queer groups and to some extent even women did not find much place in the constitution. The second half of the last century witnessed the

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<sup>1</sup> Author is an Advocate at Delhi High Court, India.

emergence of various expressed groups out of shadows and led the movement for their rights. It was in this period that the approach towards child rights was also highlighted. This also led to the recognition of their rights in various National, International laws and Statute.

One of the most notable development in the field of disability rights at the international level in the recent past is the adoption of United Nation Conventions on Rights of Persons with Disabilities (UNCRPD) adopted by the UN in 2006. This convention has also embraced the social model of disability and has stimulated the adoption of disability rights legislations based on social model of disability. Many countries including some of the BRICS countries are now modelling their Disabilities Rights Laws in accordance to this Convention.

In the history of evolution of human rights the rights of children have received the maximum ratification due to United Nations convention on the rights of the child (UNCRC) which defines child as every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier. It also awards the minimum entitlements and freedoms that should be afforded to every person and this should be done regardless of Race, nationality, colour, gender, language, religion, origin, wealth, birth, status, disability or any other such characteristics. Article 2 of UNCRC clearly mandates that the states must take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

“Despite the growing numbers of disabled adults who are having children, parents with disabilities continue to be primarily ignored by research and social policy. The sparse literature that can be found on the topic typically focuses on the relationship between parental disability and children’s well-being. In some cases, a negative impact is hypothesized, studied and ‘verified’; in other cases, the correlation between indices of dysfunction in children and parental disability is explored; and in others yet, the negative impact on children and the need to counsel them is taken as a given.”<sup>2</sup>

### **Methodology**

For the purposes of the qualitative research, I have interviewed 14 students currently pursuing graduation or post-graduation courses in University of Delhi. They are of the age group between 18 to 24 years. 7 of them have been brought up by at least one disabled parent. They have a good understanding of the impact it has had on them. Most of them have personally

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<sup>2</sup> Ora Prilleltensky, “My Child Is Not My Carer: Mothers with Physical Disabilities and the Well-Being of Children,” *Disability and Society* 19(3) (2004)

experienced discrimination and oppression at the hands of the family members or state authority. 7 of them have been brought up non disabled parents. Using their opinions and experiences, I have highlighted various lacunae present in implementation of rights of disabled parents.

Broadly speaking, there are four legislations in India regarding to disability. These are (1) Mental Healthcare act (2017); (2) Rehabilitation of council's relating to (act,1992 which spells out the psychiatric disability) major and the scope of the regulatory body, namely rehabilitation council of India ; (3)The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act, 1999; (4) The Rights of Persons with Disability act of 2016 spelling out comprehensive rights of the disabled in India.

## **II. PARENTS WITH PHYSICAL OR SENSORY DISABILITIES**

The government has brought 119 amendments to the rights of persons with disabilities bill, 2014 which was brought to comply with UNCRPD to which India became a signatory in 2007. The act sets the government a 2 year deadline to ensure persons with disability get barrier-free access in all kinds of physical infrastructure and transport systems.

However, school events, transportation, stores and community centers often aren't accessible to people with disabilities. One of the subject reported that often times her parents couldn't send her to various picnics or after school events organised by the school or couldn't let her participate in sports whose practice couldn't be held during normal school hours till she was 15 as her parents suffered from visual disability and couldn't find a way other than walking all the way to her school and that too without a guide to pick her up, as the school bus didn't operate at all hours. As she turned 16, she started going to and from her school all on her own so her parents used to help her hide her mobile phone in her bag so that she could keep them updated about her whereabouts whenever she was required to.

It is often assumed in such situations that the child and the parents are in 'role-reversal' with their parents, rather than in a typical type of parent-child relationship. But as can be seen from the

above example, Disabled parents are already experts at adapting to a largely inaccessible world, which makes them well suited to the challenges of parenting.

Most of the subjects noted that they were being constantly bullied and ostracized by their peers. One of the subject noted how his mother was never invited to any family event or even when invited was to made to sit as an ornamental piece even by his own grandmother. Often he would

the hear the remark that she wouldn't be able to do this or that because of her disability which was completely untrue as he had been raised single-handedly by his mom since his birth.

Issues also include events without a Sign Language interpreter, movies that don't offer closed captioning, sidewalks without curb cuts, public transportation without wheelchair lifts or elevators and restaurants and facilities with stairs instead of ramps etc.

Most of the subjects discovered an underlying personal strength that enabled them to overcome these experiences, and all but one maintained a close and warm relationship with their parents.

The majority of the subjects recalled happy, if not necessarily carefree, childhoods. Only one regarded her childhood as wholly unhappy. Most of the subjects expressed positive feelings of love and affection towards their parents, and all have maintained close contact with their parents. As children of parents with stigmatized conditions, they tend to learn about oppression, empowerment, and civil rights from an insider perspective and at an early age.

While speaking with subjects raised by Disabled and Non disabled parents most of them agreed on how many friends they had, bedtimes, how active they were after school. They ate dinner with their family most nights of the week, was monitored by their parents while using the Internet and were assisted in their homework. They all described their families similarly. Finally, children raised by disabled parents reported that they were more comfortable around people with disabilities than children raised by parents without disabilities. They were constantly surprised by the fact that the disabled parents of those children could cook, clean, do laundry, go to the market or even attend their school events such as annual day or sports day.

### **III. PARENTS WITH PSYCHIATRIC DISABILITIES**

The available research suggests that factors unrelated to disability often have a more significant impact on parental fitness than does disability itself. The research also suggests a tremendous variance in the impact that disability has on parental fitness. Importantly, parenting services have been shown to make a difference for many parents with insufficient parenting skills. While few conclusions can be drawn about the parenting abilities of developmentally disabled parents as a group, it is clear that individual inquiry is required before decisions are made to remove children from parents.<sup>3</sup>

When the subjects were asked if there had been any positive impact of having been brought up a parent with mental illness, most of them answered affirmatively. They mentioned that they

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<sup>3</sup> Watkins, *Supra* note 68, 1454.

feel that have become better and stronger. One could see that these subjects had greater compassion and tolerance. They had developed healthier attitudes and priorities as compared to their counterparts. They also had stronger family bonds and they experienced pride once their parent recovered.

One of the subject noted that when she went up to her father who suffered from an anxiety disorder and told him about the fact that she didn't want to go to school and wanted to just lie down in her bed all day. Her father let her and took an appointment with the therapist and taught her the importance of having a mental health day every now and then. He was also very honest about his mental health issues, which in turn made her take care of herself.

In the new Mental health care Act, 2017, India has come up with a novel provision for infants and toddlers to not be separated from their mothers unless there is any risk to the child. However, they have failed to offer a solution in the cases where older children may also have mental health needs when either parent has a mental illness and depending on their developmental level and health, they may need specific psychological aid.

Despite the increased risks associated with having a parent with a mental illness, the majority of children raised by parents with mental illness will never develop the psychiatric disorder of their parents. In fact, research has suggested that children are at heightened risk for psychopathology when taken from their parents and put into foster care. Long-term separation from a parent can result in a negative impact on the well-being and functioning of both children and parents. Thus, removing a child from his or her parent—in some situations—can ultimately cause more harm than good.<sup>4</sup>

#### **IV. LAWS IN OTHER COUNTRIES**

Scandinavian countries have been forerunners and even a source of inspiration even for many western countries when it comes to introducing laws favouring the marginalised section like the disabled. Special mention can be made of Sweden, which has served as a model in regard to the promotion of the disability rights.

The aim of the Swedish government's disability policy is to give people with disabilities a greater chance of participating in society on same terms as others. The justice system, transportation and IT are three out of the ten prioritised areas which have been given special attention. The possibility to travel without hindrance is of vital importance to people with disabilities. All citizens must be able to work, study and take part in community activities on

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<sup>4</sup> Gwillim, *Supra* note 230, 360

equal terms.<sup>5</sup>

Swedish government has inspected the country's municipalities to initiate move to make facilities such as bus and tram stops more accessible, and it is also reviewing the disability and public transportation act. Sweden has also placed special emphasis on digital inclusion in Sweden's national IT strategy.<sup>6</sup>

One important feature of the act concerning support and service or persons with certain functional impairments gives disabled people the right to personal assistance, in principle free of charge. The amount of help is determined by the extent of their disabilities.<sup>7</sup>

People with disabilities can also apply for municipal grants so that they can have accommodation modified which is suited to their needs. This grant covers all types of disabilities, including mobility disability, impaired vision, mental disorders and allergies. There is also a provision for those people who need extra support, they may live in group housing, where staff provides 24 hour assistance. Alternatively, people can also live in serviced flats, where they are completely independent but are able to call for assistance at any time. Both of these obviously are alternatives for living in family home.<sup>8</sup>

Swedish Social Insurance Agency also provides for car subsidy for those people who face great difficulty while travelling or using public transport. This agency also provides various types of financial assistance. Parents of children with functional impairments are also covered under this.<sup>9</sup>

Samhall which is a state owned services and goods provider offers people with disabilities with meaningful employment that furthers their personal development.

The city of Stockholm has significantly improved accessibility in the capital. For example:

Some 5,200 pedestrian crossings have been converted to follow the established Stockholm model – a solution that includes a ticking sound when the lights turn green, contrast markings and a distinct curb showing where the roadway begins, plus a ramp enabling people in wheelchairs to access the walkway easily.

With the help of Stockholm city's sports administration, 80 or more sports facilities have benefitted from improved accessibility with the help of their collaboration.

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<sup>5</sup> <https://sweden.se/society/swedens-disability-policy>

<sup>6</sup> Ibid

<sup>7</sup> Ibid

<sup>8</sup> Ibid

<sup>9</sup> Ibid

About 360 bus stops have been modified by raising the curb height to facilitate boarding and alighting. Sweden has also made laws against discrimination whose general purpose is to strengthen the legal protection of individual and to help victims of discrimination obtain redress and financial compensation. Acts, such as LSS, which was designed to offer people with extensive disabilities greater opportunities to lead independent live and to ensure that they have equal living conditions and enjoy full participation in community life. People who are not covered by it can seek assistance from their municipality under social services act. These and planning and building act are examples of laws containing clauses that apply specifically to disabled people.

## **V. SUGGESTIONS**

### **1. SHARED RESPONSIBILITY:**

- a) The parliament must establish more guidelines mainly via legislation with respect to the disability policies.
  - b) The executive must ensure the enforcement of the said policies. They must not only be ornamental.
  - c) District level councils must be set up which should work closely with National Federation of the Blind and must be responsible for health and welfare.
  - d) The municipalities must be made responsible for the education and social services, etc.
2. There must be amendments made to MV Act, 1988 to offer more accessibility in buses etc.. Also, special transport services should be provided by the government to such families at a very low cost.
  3. There should be programs set up for disabled people to help find affordable housing in areas which is also disabled friendly.
  4. Free coaching classes with special educators for their advancement in IT sector should be provided at all levels.
  5. At every district level, there should be specially trained therapists available for the families or children belonging to this group.
  6. One of the most important and the need of the hour is the sensitisation program, which must start from the time a child steps into a school.

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