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The dream which emancipated children with disability: A socio-legal analysis

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Abstract

Children with disability have all the rights which any other child without disability would otherwise have, as enshrined under Article 14, 19 and 21 and 21 and 21 and it is this deeply entrenched discrimination in the society itself which hampers the formative years of a child's life. Although, The Rights of Persons with Disability Act, 2016 bestow upon the person with a disability including children, various basic rights such as equal treatment; community living; protection from cruelty and inhuman treatment; protection from abuse, violence and exploitation; right to education etc. and various measures have been laid down in the Act to ensure effective implementation but it has been noticed that India is still lagging behind in achieving the legislative intent that is to include children with disabilities in the mainstream. Keeping in mind the reprehensible condition of children with disability and the legal mandate to protect the rights of such children and provide them with appropriate protection and services, various non-governmental organization have taken effective measures by setting-up institutes with the sole aim to assist, protect and rehabilitate children with disability back into normal life and survive as an independent individual. The author seeks to unveil the present scenario regarding the situation of disabled children by highlighting the international interventions, legislations, judicial perspectives, as well as the enabling role of social work towards children with disability.

Keywords: emancipation, disabled children, initiatives, social work

1. Introduction

We human beings are creatures of love and procreation. The instinct of reproducing is innate and the ecstatic feeling of becoming parents to a newborn is overwhelming. The joy of holding your own child for the first time is thrilling and unfolds a glimpse of a bright future right in front of your eyes. But, what if this future doesn't turn out as you manifested, what if the child shows no signs of normal physical and mental growth. It is at such revelation of child's disability that the parents become anxious and stressed; start searching for professional and medical advice and diagnosis. Moreover, there are certain instances, such as, no possible diagnosis, busy schedule of parents, orphaned children etc. which often leads to neglect of such children and thus results in poor living conditions and violation of human rights. The unconditional love which every parent has for their child is elusive to explain in words but there are also certain circumstance under which parents become anxious and also at times oblivious of their child's condition due to problems not within their reach. These children with disability need special attention and specialized care. Out of 753 Crore (Cr.) population surrounding the world, the largest minority is that of people with disability and the majority lie in the developing countries. Whereas in India as per the Census of 2011, out of a population of 121 Cr, around 2.68 Cr persons are disabled and about 78.7 Lakh disabled persons fall within the age group of 0-19 years $^{[1]}$. As per the World Health Organization, disability is a broad term which encompasses various impairments, activity limitations and restriction in equal participation ^[2]. The disability can either be from the very birth of the child or when he/she grows into an adult.

Thus, it is a complex phenomenon whereby the overall interaction of a person with various stimulus is affected in some or the other manner. In order to live a meaningful life, it is very important that the childhood of a person and those formative years are dealt with carefully and therefore, the focus should be on the children with disabilities. The two very influential documents reflecting the actual state of disability in children and its consequences are WHO and World Bank 'World Report on Disability' [3] which states that people with disabilities are generally poor, have lower achievements in education and have poor health as compared to people without disabilities and 2013 UNICEF's State of the World's children report on children with disabilities which mentions that children with disabilities are neglected by their families and are not able to access the local schools or health services; they are more prone to violence and are very vulnerable. Through these reports, it is amply clear that the state of children with disability is full of struggle and all the barriers impedes the growth of an individual to their fullest potential.

There have been many initiatives both national and international to protect the rights of these children but recently several organizations and special institutes have been established with the very sole purpose of assisting such children with disability and consoling the parents to be calm and positive regarding their child's condition. As Stephen Hawking rightly pointed out; "People with disabilities are vulnerable because of the many barriers we face: attitudinal, physical, and financial. Addressing these barriers is within our reach and we have a moral duty to do so. But most important, addressing these barriers will unlock the potential of so many people with so much to contribute to the world.

Governments everywhere can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education, and employment—and never get the chance to shine [4]. These children with disability hold plethora of talent and potential which needs to be cultivated through regular motivation, attention and care; the indifferent treatment which they face is a hurdle in their growth and discovering their special ability which lies deep down in their heart and mind. These souls are vulnerable to this indifferent treatment of their family and society which often results in suppression of their most inquisitive and creative mind and thus leads in stagnations and vegetative state. The government is aware and the society that these children need attention and care so that this disability does not become a barrier to success in their life. Keeping this objective in mind the author(s) have carefully study and analyzed the different legislative and judicial measures adopted by the authorities in India and also the role of non-governmental organizations to assist in this dream which emancipated children with disability to their full potential.

2. The rights of children with disability

2.1 International Initiatives

Rights are inalienable and equal for all, it would not justify the discriminatory act of subjugation refusing these incapacitated children the right to life, education, equal treatment and accessibility. Recalling the principles laid down in Universal Declaration of Human Rights of 1948 and The Declaration of the Rights of the Child of 1959, The Declaration of the Rights of the Disabled Persons (DRDP) adopted by the United Nation in the year 1975 [5], was a stepping stone towards global recognition of equal civil liberty of the disabled persons including children. DRDP demarcated the words 'disabled person' as "any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities [6]. This definition is inclusive and wide enough to include children who are physically and mentally handicapped within its scope. With the gradual lapse of time, careful understanding and observation, policies to assist disable person developed from a nascent care at institutes towards providing educational assistance for such children who are about to enter adulthood. Through correct instructions and facilities these children with disability responded better and became instrumental towards promulgating progressive disability policy. Another initiative was the United Nation Convention on the Rights of the Child, 1989 [7], wherein children with disability finds special mentioned under article 23 [8] and is predominantly based on the principle of non-discrimination. With United Nation declaring the year of 1981 as the International year of disabled persons, which facilitated the World Programme of Action (WPA) concerning Disabled Person of 1982 [9]; further culminating with the Standard Rules on the Equalization of Opportunities for Person with Disabilities of 1993 [10], which were motivated through the learning acquired during the UN decade of persons with disability (1983-1992).

Moreover, at the regional level, the decade from 1993-2002 was declared as the Asia and Pacific Decade of Persons with Disability by United Nations Economic and Social Commission for Asia and Pacific (ESCAP) [1] and adopted

"The Proclamation on the Full Participation and Equality of People with Disability in the Asia and Pacific Region" at Beijing [12], which was further extended for a decade from 2003-2012, under the agenda encouraging inclusive, barrier-free and rights-based society for disabled persons in the Asian and Pacific region in the twenty-first century [13], during with the Incheon Strategy to "Make the Right Real" was introduced and the initiative was even further extended to 2022 [14]. Thereafter, The Beijing Declaration, including the Action Plan to accelerate the implementation of the Incheon Strategy [15], was adopted in 2018 which also display synergy with the 2030 agenda for Sustainable Development goals of ESCAP.

In the year 2006, UN General Assembly adopted the Convention of the rights of persons with Disability (CRPD) and its Optional Protocol [16], inspired by the decades of work by UN attempting to atone the attitudes and methodologies toward persons with disabilities. The focal shifted from viewing disabled persons as "objects" of aid, medical assistance and shared protections to viewing persons with disabilities as "subjects" with liberties and competent to claim those rights and capable to form free and informed consent for their lives. The CRPD came in to force in 2008. Whereas, Article 7 of CRPD provides for rights and protection of rights of disabled children through appropriate measures. It provides children with disability the right to equality with other children, the principle of best interest and the freedom to communicate without obstruction [17]. Further, Article 18 (2) speaks regarding the rights of disabled children to a name, right to nationality and the right to be cared by their parents [18]. Article 23 (1) (c) enunciate that disabled children shall have right to preserve their fertility on the same footing to that of other and under Clause (3) it provides right to a family and methods to check suppression, relinquishment, neglect and exclusion of these children with disability from there family [19]. Article 24 lay emphasis on the right of disabled children to free and compulsory education, either primary or secondary [20]. And various other rights and preventive measures are inculcated in the CRPD in respect of disabled children [21].

Analysing from a bird's eye view of the instrumental declaration and conventions of the world organizations to protect and uplift that section of the world which is a minority yet forms an important part of the population; disabled children, is commendable. These conventions have inspired and pushed the governments of various country to enact laws relating to disabled person including children and establish institutes to safeguard their interest and rights.

2.2 India's obligation under international initiative

"Persons with disability in India are the most neglected and least served strata of society [22]. Similarly, children with disability are also not given much impetus in Indian policymaking until recently. The Grund Norm of India, even though enunciate the right of the state to promulgate special law for children [23] nonetheless, does not embrace any provision under the third chapter which provides for equal opportunity and treatment to persons with disability irrespective of their age [24]. The first legislative initiative which attributed protection of rights of disabled persons including disabled children in India was in the year 1995 when the parliament passed, The Person With Disability (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 in consonance with the UN

ESCAP, Proclamation on "The Full Participation and Equality of People with Disability in the Asia and Pacific Region ^[25]. The 1995 Act was a comprehensive act and primarily focused on the role of the appropriate government to "protect" and "promote" the rights of disabled persons including children with disability; to "endeavour" and "ensure" to all children with disability access to education and vocational training facilities. This beneficial legislation even though not specifically drafted for children with disability, did lay down the essential inalienable rights of children with disability and the burden was on the appropriate government to fulfil the needs and essential requirements of these children with disability to assist them to become independent.

The most recent legislation for the benefit of children with disability was enacted in the year 2016, giving effect to the UN CRPD [26]. As the old saying goes, 'it's better late than never'; India rectified UNCRPD on October 1, 2007, but only enacted legislation on the principles laid down in the said convention in the year 2016 when the Indian parliament passed the Rights of Disabled Persons Act of 2016. The highlights of the Act of 2016 are as follows:

- Based on the principles such as respect for inherent dignity and independence of person, nondiscrimination, full and effective participation, respect for difference and acceptance, equal opportunity, accessibility, equality and respect for evolving capacities of children with disability.
- 2. Provides an extensive definition of important terms such as discrimination, inclusive education, person with benchmark disability, person with disability, person with disability having high support needs, etc.
- Rights of disabled person including children i.e. right against discrimination, right to personal liberty and right to reasonable accommodation, right to protection and safety, right to reproduction and family, right to vote and access to justice.
- 4. An entire chapter [27] is provided for promotion and providing appropriate means to educate children with disability; skill development and employment; social security, health, rehabilitation and recreation.
- Children with benchmark disability are provided free education [28].
- 6. Persons with at least 40 % disability are entitled to certain benefits such as reservation in education and employment, preference in government schemes and so on
- 7. Regulation of establishment of institutes for persons with disability and grants to such institutions.
- 8. National and state funds for persons with disability
- Specific offence against person with disability are provided and also the establishment of special courts for providing speedy justice to persons with disability.

The Act of 2016 is a comprehensive act which deals with person with disability, children with disability and their rights, the duty of the government and the role of other institutes in assisting the state to fulfil this obligation to support and protect persons with disability including children to ensure independence and confidence in them. Literature have displayed that disabled children are suspiciously susceptible to rage, violence, neglect, and abuse as a consequence of exclusion and discrimination [29] An explicit quantity of proof have shown that large number

of disabled children lack the protection in terms of various services such as medical, social and legal aid [30]. The condition of children with disability is not as it is proposed by the act, should be, but instead, these children are repeatedly sequestered and may have less prospect for reporting or receiving support. Drafting legislation and enacting laws is not the end in itself but just a framework on which the concerned non-governmental and governmental organization work. It's the work at the ground level which actually assist and emancipate these children with disability.

3. Judicial observations on children with disabilities and access to education

Education is such a tool which, if provided evenly to all the classes of persons in any society, has the power to emancipate anyone from the demons of discrimination and injustice. It is noteworthy that children with disabilities face various forms of discrimination at all levels which lead to their ostracization from society. Because of the differential treatment, lack of resources and lack of willingness to accommodate the interests of such children the suffering of disabled children is only escalating. They are even neglected in educational institutions which does not only violate their right to education as guaranteed under Article 21-A of the Constitution of India but is also against the principles provided under Rights of Persons with Disability Act, 2016. For some of them, even access to education is a far-fetched dream because of variety of reasons discussed earlier. The 2016 Act aims for the full participation and equality of people with disabilities so that everyone could study together, learn together and grow together. The main idea behind the said enactment was to bring the left outs into the mainstream and this can only be achieved through 'inclusive education'. One of the salient features of the Rights of Persons with Disabilities Bill, 2014 is that, that all educational institutions funded by appropriate Government shall provide inclusive education to the children with disabilities.

Key features in the Act which encourage educational accessibility and inclusive education to children with disabilities are: -

- 1. The act envisages 'inclusive education' to the children with disability and the same has been defined under section 2(m) of the 2016 Act [31]. By inclusive education, the legislative intent is not only to facilitate an environment where all children whether with disability or without disability could learn together but also provides that the system of teaching and learning is suitably adapted to the needs of disabled children.
- 2. 'Public Facilities and services' can also be established to deliver basic services to the public at large. Through this provision various educational and vocational training center are created in different states specially for children with disabilities [32]. In the case of *Rajive Raturi vs. Union of India* [33] the Supreme Court has held that the visually impaired persons are required to be provided with proper and safe access to roads, mode of transportation as well as to buildings, public places etc.
- Non-Governmental Organizations and other cooperative societies have come up to provide adequate facilities to disabled children as and when required [34].
- 4. It is incumbent upon the educational institutions that are funded or recognized by the appropriate Government to

provide inclusive education to the children with disabilities and in furtherance of this, they should not be treated with discrimination and should be provided with equal opportunity as others. The pedagogy, accessibility of resources, transportation, accommodation, participation and other suitable developmental needs of such children are all well within the duties of such educational institutions [35]. The non-compliance of any provision shall be punishable with fine which may extend to five lakh rupees for any subsequent contravention [36].

- 5. Specific measures to promote inclusive education to be taken up by the appropriate Government and the local authorities [37].
- a. To conduct survey of school going children in every five years for the identification of the number of children with disabilities.
- Establishment of adequate number of teacher training institutions and employment of such teachers who are equipped for teaching children with different kinds of disabilities.
- Training of professionals and staff to support inclusive education.
- d. Establishment of resource centres to support educational institutions.
- e. Incorporation of appropriate modes of communication like Braille and sign language to support children who are blind or deaf.
- f. Providing books, learning materials and other assistive devices to students with benchmark disabilities free of cost up to the age of 18 years.
- g. Providing scholarships to students with benchmark disabilities.
- h. Making Suitable arrangements in the curriculum and examination system to meet the needs of such children like giving extra time for completion of paper, facility of scribe etc.
- i. Focusing on research to improve the learning.

3.1 Inclusive Education or special schools for children with disability? The legislative v. judicial perspective

While the 2016 Act encourages the outlook of inclusive education of disabled children to put them into the mainstream with other children, the judicial notion about the education system of such children is somehow not on the similar lines. Recently, in a PIL filed by a petitioner before the Supreme Court in *Rajneesh Kumar Pandey v Union of India* [38] (2016) which is still pending, the concern put forth was lack of special education teachers in Uttar Pradesh to teach as well as train the disabled children. The petitioners also sought directions from the concerned State Government in this regard. There were several problems that were highlighted in 16 special schools for disabled children, for instance: -

- 1. No hearing-impaired specialized teacher.
- 2. Only 4 classrooms for 145 students
- 3. No bus/van
- 4. No Hostel Warden
- 5. Requirement of residential buildings and separate building for girls.
- 6. Shortage of braille teachers, sports teacher and computer teacher
- 7. No medical room

While passing an interim order to the concerned authorities

of State of Uttar Pradesh, the Court also made an observation in which it was contended that "it is nearly impossible to include disabled children who are suffering from mental retardness, blindness, autism or other like disabilities in the mainstream schools for the sake of education and therefore, there is a definite need of separate schools with distinctly trained teachers." The very opinion of Hon'ble judges might be a pragmatic solution to the impugned situation in hand, but the same is contrary to the legislative intent provided by the 2016 Act on Rights of Persons with disabilities Act. Although there are very few provisions which deals with the education of children exclusively but nevertheless Section 17 of the Act puts enough emphasis on the efforts that should be taken up by the appropriate government and local authorities to provide inclusive education to such children. In this context, when such highly opinionated observations are made by the apex judicial body, the overall purpose of the creation of such provisions is defeated.

In the case of *Disabled Right Group and Anr. Vs. Union of India and Ors* [39] it has been reiterated by the Supreme Court that the discrimination and oppression against disabled children is deeply entrenched into the society which lead to the differential treatment and inequality of such children. But it is also not impossible to create a level playing field which can be achieved by a constant attempt to not only ensure that the children are getting education but also that such education is imparted to them in a fruitful manner. Thus, for the holistic development of children with disability, proper accessibility to the buildings where the educational institution is situated and other areas like hostels, classrooms, library, bathroom should be taken care of

In Payel Sarkar v. Central Board of Secondary Education and Ors [40]. The petitioner (a student) was not allowed to sit for the All India Senior School Certificate examination because she was debarred from giving exam due to her frequent absence from school. The Court accepted that her poor attendance record was only because of a "special learning disability" and in furtherance of that, reviewed the policies and by laws of the school and found that there was no special provision to accommodate the interests of such children. In the end, the Court held that the rigidity of attendance should be relaxed for such disabilities and the policies should be inclusive enough to accommodate the children with special learning disability.

Therefore, through these judicial perspectives on access to education and more particularly inclusive education it is amply clear that the focus has now changed from sending children with disabilities to special schools to sending them to public schools where the schools will be responsible to accommodate such individuals. It is pertinent to note that this shift has also been noticed not only in India but other countries also. For instance, In the matter of Moore v Her Majesty the Queen in Right of the Province of British Colombia [41], The Canadian apex Court stated that the children with disabilities have all the rights to avail the services of public education and the onus shifts on the Government and appropriate authorities to equip the education system in such a manner that the interests of such children are accommodated and practiced smoothly.

Similarly, in the USA there were two important cases, Pennsylvania Association for Retarded Citizens v Commonwealth of Pennsylvania [42] and Mills v DC Board

of Education [43] which finally culminated into granting students with disabilities access to education within public schools. In the Pennsylvania case, it was contended by the association for citizens with mental retardation and the parents that their children were not allowed to attend public school. Later, the Court held that by denying these students access to education the basic tenet of equal protection and due process has been violated, therefore, the schools were ordered to immediately rectify their decision and admit those students. In the Mills case, seven students were expelled from the school due to behavioral disabilities and again the judges held in favour of the children that, regardless of the severity of the disability, the students shouldn't be denied education at any cost.

Considering afore mentioned Supreme Court's and foreign Court's observations, it can well be said that as far as possible the differently abled children should be accommodated reasonably in public educational institutions and should be treated at par with the children without disability.

4. Social work and children with disability

There are few among the masses who actually change themselves or their work in order to bring the change in the society, you either call them philanthropist, humanitarian or social workers. Keeping others benefit and welfare over yours own is a challenge which not everyone seems to tackle in this fast-moving, technological advance and economically driven society. Yet few individuals set up welfare organizations for the betterment of the underprivileged of the society either with or without the aid of the state. There are institutes set up with the sole purpose of emancipating children with disability by protecting their rights and promoting the right practices which assist them to develop the right mental and physical attitude and become independent individuals in the society.

The very first question which encompasses our mind is what does a children's disability social worker do? These workers work at the ground level to help connect the missing link between the institute and the parents of the disabled children. Professional social workers have plenty to contribute towards children with disability be it either nongovernmental or governmental organizations. These workers are focused on their active role while they provide unique and valuable assistance to targeted persons in order to fulfil the complex needs of these children with disability, their family and community.

The work of setting free these children with disability by education, prevention and treatment cannot be done by an individual alone but instead it requires group effort. There are organizations established by the government and also non-governmental organizations, which work for this very sole purpose of assisting disabled persons. As per a report of Centre for the Study of Social Systems, School of Social Sciences, Jawaharlal Nehru University [44], there are around 84 non-governmental organizations/ Disability persons' organizations in India out of which only few are primarily concerned and focuses on children with disability; i.e. Disha Centre for Special Education, an institute established to provide opportunity to children with physical, mental and multiple disabilities for children at Jaipur, Rajasthan; Alpha to Omega Learning Centre for Children with Disabilities at Chennai; Samveda Training & Research Centre at Davangere, Karnataka; Institute of exceptional Children etc.

There are not plethora of institutes which primarily focuses on children with disability in India but with gradual shift in the notion of uplifting youth of the country, rising awareness of the parents, increased governmental support, importance of social work for disabled children and the need to protect and promote their individuality and independence, it is anticipated that new specialized institutes are being established every passing year.

5. Conclusion

At first the society was ignorant of the wrongs committed against disabled persons. A person born with disability was considered destined to suffer pain and suffering until the 20th century. The adoption of UDHR and DRDP which at its inception initiated rippling wave of recognition of rights of disabled persons, of wrongs against disabled persons as violation of human rights and a change in the society's perception. All humans are equal irrespective of their ability or disability to act in a certain way and excluding children with disability would be an incorrect interpretation. Through the above discourse it is amply clear that even though there exists a frame work at national and international level and many efforts are also made at the grass root level to improve the living conditions of children with disability but there are still many lacunas in the law itself and the mechanism of implementation which needs to be addressed. There is no specific legislation which addresses the situation of children with disability holistically. The 2016 Act on Rights of Persons with disability highlights some general provisions for the persons with disability and the mention of children with disability and their concerns is not comprehensive enough to tackle the ongoing discrimination against them. If we talk about the status of their education then again it has been seen through various WHO and UNICEF world reports on disability that the condition of education to such children is only worsening. Some children do not even have the chance to access the schools and if they can then the schools and other educational institutions are not equipped to the special needs for these children. Time and again there have been many cases in which it has been seen that either there are no proper hostels, or transportation facility or medical rooms to accommodate the special interests of such children. The main aim of CRPD and the 2016 Act was to bring these children in the mainstream by creating a level playing field for these children at par with others but to achieve inclusion of disabled children in the society; the journey remains unaccomplished. Lastly, it is also pertinent to mention the laudable role of social workers and specialized institutes in emancipating these children with disability. There exist only a few institutes which specifically focus on assisting and facilitating these children to become independent individuals. The success stories of children who are of the age of fifteen years but still fail to hold a spoon or walk properly, when organically learn such innate and instinctive behaviour as a result of the time and work devoted consistently by these institutes or social workers, make us believe that every child of this nation can be emancipated of his or her disability, if not, only to an extent which is possible, to make them independent adults; the endeavour continues.

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