



Journey of persons with disability from being viewed as ‘objects of rights’ to ‘agents of rights’

Isha Khurana

Doctoral Research Scholar

Indian Law Institute

Abstract

Persons with Disability constitute 15% of the world’s population; still they have remained invisible to the international community till recently. There has been lack of recognition of the rights of persons with disability along with nominal to no representation from them in drafting of the international instruments that affirm their rights and needs. Persons with Disability were primarily seen as objects and then subjects of rights. However, a much-needed inclusive and participatory approach was adopted while drafting the United Nations Convention on Rights to Persons with Disability (CRPD). Here, they were being treated as agents of change and their lived experiences with disability formed the very backbone of the affirmations and rights captured in the International Convention.

Through this research paper, the researcher is trying to trace the journey experienced by the Persons with Disability from being a ‘Subject’ of rights to ‘Agents’ of rights. The journey is being examined post the formation of the United Nations and has been roughly apportioned in four segments, I Lack of visibility of Persons with Disability; II Subject of Rehabilitation and Integration; III Objects of Human Rights and IV Subjects of Human Rights. Each of these segments captures the international instruments for persons with disability that were adopted and an attempt has been made to understand extent of rights of persons with disability captured by them.

Introduction

ONE BILLION PEOPLE, or 15% of the world's population, have some form of disability. People with disabilities are more vulnerable to negative societal and economic outcomes, such as lower levels of education, high poverty rates, and inaccessibility to healthcare services, to name a few. Unfortunately, disability increases the risk of poverty by limiting employment and educational opportunities, lowering wages, and raising the cost of living. This was exacerbated further by the ongoing pandemic.

Disabled people have long been subjected to a variety of forms of discrimination and mistreatment. On the basis of the broader equality discussion, there is a need to strengthen and deepen understanding of disability and their needs and experiences, so as to promote the interests and rights for people with disability.

Awareness about disability and disability-inclusive development often termed as inclusive development is increasing especially after coming in force of the United Nations Convention on the Rights of Persons with Disabilities (hereinafter referred to as CRPD) in the year 2008. Currently, 177 countries have ratified the CRPD, and several of them have enacted domestic legislation to comply with the Convention.

Disability is relatively a latecomer to the categories of equality and human rights, and it took decades for disability to be recognised as a human rights issue. Internationally, the journey of people with disabilities can be traced from being labelled as non-productive citizens to being recognised as subjects of human rights. This recognition as "rights holders" occurs in four stages. These stages also reflect the ideological shift in our treatment and recognition of people with disabilities from 'objects of rights' to 'holders of rights.'

In this research paper, the researcher attempts to trace the journey of how persons with disability became the subjects of human rights and participated in the framing of UNCRPD. For this, a regulatory analysis has been undertaken for the international human rights documents, promulgated post the establishment of United Nations, along with other international treatise that had a potential impact on the rights of the persons with disability.

I. Lack of Visibility of Persons with Disability

The early human rights documents; the United Nations Declaration for Human Rights, 1948; the International Convention on the Elimination of All Forms of Racial Discrimination, 1965 and International Covenant on Civil and Political Rights & International Covenant on Economic, Social and Cultural Rights, 1966; drafted during 1945-70 had not made any explicit references to persons with disability.

It is surprising to note that even though the two¹ out of the nine members of the drafting committee of UDHR had members who had experiences with disability, there was no recognition of the vulnerabilities faced by persons with disability. Rather a stray reference to disability only mandating social security in an event or a condition, like unemployment & sickness under Art. 25 of the UDHR.²

Subsequently adopted International Convention on the Elimination of All Forms of Racial Discrimination, 1965 and International Covenant on Civil and Political Rights & International Covenant on Economic, Social and Cultural Rights, both in 1966 also did not explicitly recognized Persons with Disability as a group of people who have rights.

It is interesting to note that, although, Helen Keller addressed world leaders in the United Nations General Assembly in 1950, Persons with Disabilities remained an unseen group of citizens who were not on the radar throughout the early stages of the implementation of human rights treaties.

One can say that the struggles & vulnerabilities experienced by persons with disability lacked visibility and traction while the core international human rights treaties were being drafted, thus explaining its absence from the dominating discourses at that time.

II. Subjects of Rehabilitation and Integration 'as far as possible'

The early decades of the United Nations had limited discourse on the rights of the disabled but this changed in the second phase 1970-1980, where the persons with disability were being viewed as the aspects of rehabilitation and integration in the society, as far as possible. This decade was marked with adoption of two non-binding declarations pertaining to persons with disability by the General Assembly, these were:

¹ Eleanor Roosevelt, Chair of the Drafting Committee of the United Nations Declaration on Human Rights, was the wife of United States of America President Franklin D. Roosevelt, who had experienced locomotor disability and had to resort to the use of wheelchair and John P. Humphrey, the Canadian member, had lost an arm following an accident while playing with fire.

² UDHR, Resolution A/RES/3/217A. December 10, 1948, Art.25.

Declaration on the Rights of Mentally Retarded Persons

In 1971, General Assembly passed a Declaration on the Rights of Mentally Retarded Persons. This was drafted by an international Non-Governmental Organization, the International League of the Societies for the Mentally Disabled and contained only seven paragraphs along with a preamble. This declaration was edged with its firm belief in the medical model of disability and granted persons with cognitive impairment same rights as other human beings but only to the *maximum degree of feasibility*.³ It therefore, treated disability is a potential barrier to exercise rights and duties.

While, this declaration was reaffirming the faith in human rights and made an attempt to promote higher standards of living, employment and conditions of economic and social progress and development for mentally retarded persons. There was absence of autonomy in exercise of the civil and political rights and for this guardian were vociferously advocated for in the declaration.⁴ It further does not view denial & restriction of human rights to persons with cognitive impairment as a human rights violation, as long as it was done with proper legal safeguards to prevent abuse.⁵

The Declaration on the Rights of Mentally Retarded Persons, 1971 was a soft law and emphasis on the right to medical care and physical therapy of mentally retarded persons just with the motive of rehabilitating them in society.⁶

Declaration on Rights of Disabled Persons

Subsequently 1975 Declaration on Rights of Disabled Persons recognized and demanded that the persons with a disability be given human rights at par with non-disabled persons.⁷ It explicitly mentions, “*Disabled persons have the inherent right to respect for their human dignity*”; thereby upholding the fundamental right to enjoy a decent life, including social and economic rights.⁸

It also acknowledged that people with disabilities have the same civil and political rights as other people.⁹ It requires them to live and enjoy life with their family or foster parents, as well as take part in all social, creative, and recreational activities.¹⁰

A careful reading of the declaration reveals that the drafters intended for it to include equality for people with disabilities. This equality is not without qualifications; it comes with some limitations, such as the limited applicability of equality rights to people with intellectual disabilities.¹¹ It is disheartening to note that a distinction has been made based on the genre of disability, resulting in sub-categorization of people with disabilities.

Despite the shortcomings, the Declarations of 1971 and 1975 were one of the first declarations that recognize the rights of persons of disability. 1975 Declaration was the first International Document wherein the need for consultations with the organizations of the persons with disability was acknowledged and emphasized upon¹².

³ Declaration on the Rights of Mentally Retarded Persons, 1971, para 1

⁴ Id. para 5

⁵ Id. para 7

⁶ Id. para 2.

⁷ Declaration on the Rights of Disabled Persons, 1975, para 3.

⁸ Id. at para 7.

⁹ Id. at para 4.

¹⁰ Id. at para 9.

¹¹ *Supra* note 11.

¹² Declaration on the Rights of Disabled Persons, 1975, para 12.

III. Objec8ts of Human Rights: Equalization of Opportunities (1980-2000)

The third phase of the evolution of recognition of human rights for persons with disability spanned over two decades and was initiated by the General Assembly's proclamation that 1981 would be the International Year of Disabled Persons and stressed on the need for a Plan of Action Concerning Disabled Persons. This was just the beginning of the main streaming the conversations on the rights of persons with disability.

+ World Programme of Action concerning Disabled Persons

In 1981, the International Year of Disabled Persons¹³ was kicked off and it brought attention to disability policy as an issue. A dedicated year for disabled persons was just the beginning of a more active phase for recognizing the human rights of Persons with Disability. This dedicated International Year led to the adoption of a detailed action plan: The World Programme of Action Concerning Disabled Persons¹⁴, hereinafter referred to as WAP.

The Programme of Action concerning Disabled Persons is an exhaustive documentation based primarily on the traditional approach of 'definition'; 'prevention' & 'rehabilitation'. Though a new dimension with respect to 'equalization of opportunities' to achieve the twin goals of 'full participation' and 'equality' have also been mentioned. It contains dedicated parts to the recognize the human rights of Persons with Disability and contained detailed recommendations for actions relating to social security, education, employment, recreation, culture, sports and religion¹⁵ at the national, regional and international levels.

It is pertinent to mention that the General Assembly recognized that WAP is an ambitious action document and therefore to ensure its implementation, an International Decade of Disabled Persons, 1983-1992, was declared¹⁶. This decade was momentous as the discourse around disability, especially cross sectional vulnerability faced by women with disability gained traction. Numerous international law instruments acknowledged the varied rights of persons with disability. A few of the prominent ones, including the reports by the **Special Rapporteurs are dealt with in the succeeding section.**

+ International Labor Organization Convention 159

During the International Decade of Disabled Persons, the International Labor Organization adopted International Labor Organization Convention 159, also known as Convention 159, on Vocational Rehabilitation and Employment in 1983. This was the first legally binding human rights treaty to mention persons with disabilities, and it was a ground-breaking international document because, for the first time, a dialogue about multiple vulnerabilities in the form of "women with disabilities"¹⁷ was initiated.

Convention 159 expanded on the premise of the 1975 Declaration of the Rights of Persons with Disabilities by stating that representative organisations of workers and employers should be consulted¹⁸. Although the convention's scope was limited, it aimed to establish principles for rehabilitation and employment policies¹⁹ for the disabled, as well as to impose obligations on state parties²⁰ to implement those principles.

¹³ General Assembly Resolution 31/123.

¹⁴ General Assembly Resolution 37/52.

¹⁵ World Programme of Action Concerning Disabled Persons, 1982, para 108-137.

¹⁶ *Id.* at para 11.

¹⁷ Convention No. 159, art. 4

¹⁸ *Id.*, art. 5.

¹⁹ *Id.*, part II.

²⁰ *Id.*, part III.

✚ **Special Rapporteurs for Human Rights of Persons with Disability.**

Simultaneously, during the International Decade of Disabled Persons, 1983-1992, United Nations Commission on Human Rights issued two reports on Disability-related Human Rights issues.

Erica-Irene A. Daes, Special Rapporteur of the Sub-Commission on the Prevention of Discrimination and Protection of Minorities, undertook the first study on persons with psycho-social disability, titled as *Principles, Guidelines and Guarantees for the Protection of Persons detained on the Grounds of Mental Ill Health or Suffering from Mental Disorder*²¹.

Daes's Report was followed by a study commissioned by Leandro O. Despouy, Special Rapporteur from 1984 to 1991. The final report submitted by Leandro along with written statements²² was published in 1991, titled as 'Disabled Persons and Human Rights'²³. It recorded widespread evidence of human rights violation and recommended the establishment of an international ombudsman for persons with disability. The report has been instrumental in placing disability on the agenda of several human rights bodies of the United Nations.²⁴

✚ **Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care**

Subsequently, prior to the International Decade of Disabled Persons coming to an end, in 1991, General Assembly adopted Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care²⁵, hereinafter referred to as MI Principles. These principles recognize the legal capacity of persons with mental illness along with demanding affirmative action from the community. These principles also form the basis of various rights being recognized and advocated for the disabled under the Convention for Rights of Persons with Disability.

At the end of the decade, 3rd December was declared to recognize as an International Day of Disabled Persons in order to raise awareness about persons with disability.²⁶ This decade built in a more nuanced understanding of disability law, rights of persons with disability, the marginalization and stigma being experienced by them and brought the disability rights discussion in the forefront.

The International Decade of Disabled Persons concluded with the adoption of the non-binding instrument: Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993.²⁷

✚ **Standard Rules on the Equalization of Opportunities for Persons with Disabilities**

The rules incorporated have been drafted in the backdrop of WAP and encompass the development during the preceding decade. These rules were rights-based and consisted of four chapters concerning

²¹Erica-Irene A. Daes, *Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder*, 1986, available at: http://hrlibrary.umn.edu/Principles%20Guidelines%20and%20Guarantees%20for%20Protection%20Mental%20Disorder_Daes.pdf (last accessed on March 25, 2019).

²² Disabled Peoples' International: submitted a written statement on inclusion of Independent living as an alternative for persons with disability as opposed to institutionalization available at: <http://hr-travaux.law.virginia.edu/document/crpd/ecn4sub21991ngo37/nid-1166> last accessed on March 25, 2019. Also see, Human Rights Advocates <http://hr-travaux.law.virginia.edu/document/crpd/ecn4sub21991ngo42/nid-1169> (last accessed on March 26, 2019).

²³ El Hadji Guisse, Report of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, 1991; available at: http://uvallesc.s3.amazonaws.com/travaux/s3fs-public/E-CN_4-1992-2_E-CN_4-Sub_2-1991-65.pdf (last accessed on March 26, 2019).

²⁴ UNHCR calls for its implementation in 1992.

²⁵ General Assembly Resolution 46/119.

²⁶ General Assembly Resolution 47/3.

²⁷ General Assembly Resolution 48/96; available at: <http://www.un.org/disabilities/documents/gadocs/standardrules.pdf> (last accessed on March 03, 2019).

'equal participation'; 'target areas for implementation'; 'implementation measures' and 'monitoring mechanism'.

The terminology used was in light of emerging modern disability rights movement. There was a progressive shift in defining 'disability'²⁸ and 'handicap'²⁹ and for the first time, a distinction was made been need to address individual needs and the shortcomings of the society. Terms such as 'independence' or 'personal assistance service' have been used in place of 'institutionalism' and 'caregivers'.

One of the major departures from WAP was the provisions for a monitoring mechanism. Until 2014, Special Rapporteur³⁰ used to be appointed by the Secretary-General who was in turn advised by a panel of experts to monitor the effective implementation of these Rules. This panel of experts consisted of representatives from six international organizations³¹ namely Disabled Person's International, Rehabilitation International, World Federation of the Deaf, World Blind Union and Inclusion International.³²

Inspired by other social movements including the civil rights movement and the women's movement, there was an emergence of disability rights movements during the International Year and the International Decade. The Persons with disabilities became politicize and started to speak up for themselves. Thus, with enactment and implementation of The Standard Rules, Persons with Disability became directly involved in the United Nations and initiated the journey of becoming the agents of their own cause.

The third phase gave immense momentum to the disability rights movement and by the fourth phase in the new millennium the disabled were vociferous of their own rights and no longer needed others to be shape rights for themselves. This was quickly succeeded by the fourth phase wherein persons with disability, individually or through organizations were the agents of human rights for themselves.

IV. Subjects of Human Rights

Till 2000, non-disabled experts were instrumental in policy and lawmaking and people with disability had been mainstreamed. The discussions were majorly concerning social policy and did not involve rights. Gradually, disability movements had gained momentum and persons with disabled along with the disabled persons' organizations were voicing their own opinions and didn't require mouthpieces. They were no longer prepared to allow others to speak for their behalf.

In this fourth phase, starting with the new millennium, there was a gradual shift from being treated as the 'objects of human rights' to being the 'subjects of human rights' along with being the agents of their human rights for persons with disability. The international disability policy had become a rights-based policy. Demands for long felt disadvantages such as equality, freedom, legal capacity, independent living, capacity building, solidarity etc. grew louder.

²⁸ General Assembly Resolution 48/96, para 17.

²⁹ *Id.*, para 18.

³⁰ Three Special rapporteurs have been appointed to monitor the working of the Rule, namely Bengt Linqvist (1994-2002); Sheikha Hisaa Khalifa bin Ahmed al- Thani (2003- June 2009) and Shuaib Chalklen (2009-2014) available at <https://www.un.org/development/desa/disabilities/about-us/special-rapporteur-on-disability-of-the-commission-for-social-development.html> (last accessed on March 26, 2019).

³¹ Monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1996, available at: <https://www.un.org/development/desa/disabilities/monitoring-the-implementation-of-the-standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities-a5256-report-on-first-mandate-of-the-special-rapporteur-part-1.html> (last accessed on March 26, 2019).

³² Michailakis (1999)

First time, in 1987, Italy introduced a proposal for a disability-specific Convention at a global level, which was followed, in 1989, by a proposal by Sweden.³³ But it was in March 2000, during the World Summit on Disability in Beijing that need for Convention was acknowledged and there was a call for a legally binding convention³⁴. The member nations urged for the adoption of a convention, which would address primary concerns of Persons with Disability. It stated: “*We hereby send out a call to action to all concerned with equality and human dignity, to join together in widespread efforts embracing national capitals, towns and cities, remote villages, and United Nations forums, to ensure the adoption of an international convention on the rights of all people with disabilities.*”

Thereafter, the call for a Convention grew louder among the nations. The Mexican President, Vincente Fox, called for a convention in his address to the General Assembly’s annual General Debate in 2001³⁵ and gave a high level of political commitment to this cause. This was followed by the New Zealand Government’s adoption of a National Disability Strategy, which aimed to investigate and support efforts to develop a Convention at the United Nations.³⁶

This multiplied the efforts of various members to constitute an Ad Hoc Committee of the General Assembly and subsequently a resolution was passed “*to establish an Ad Hoc Committee, open to the participation of all Member States and observers of the United Nations, to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities...*”³⁷

After years of lobbying and discussions for the need of a Convention for Persons with Disability, the Ad Hoc Committee met for the first meeting in July 2002. This meeting was chaired by Ecuador’s Ambassador Luis Gallegos and was open to all the member states of United Nations. After deliberations for four years on different aspects of vulnerability and other core issues such as legal capacity, supported decision making, forced intervention and institutionalism among others, **The Convention on Rights of Persons with Disabilities was promulgated by the United Nations in 2008.**

United Nations Convention on Rights of Persons with Disabilities

A Working Group was constituted in the second session of the Ad Hoc Committee in June 2003, to enable participation of all stakeholders, established to prepare and present a draft text of the Convention, which would then become the basis for negotiations by the member states. This Working Group comprised of representatives of the member states, nongovernmental organizations and national human rights institutions.

It was in the Working Group³⁸ that for the first time, Disabled persons’ organizations and the government was sharing a table to negotiate a legally binding text. This meant that Disabled persons' organizations had become actors in shaping human rights and were no longer mere subjects. However, the task of the Working Group was not easy, there were two different languages spoken- one of the Disabled person organizations and other of international human rights lawyers. Unfortunately, there was a lack of

³³ Arlene S. Kanter, *The Development of Disability Rights under International Law: From Charity to Human Rights* 39 (Routledge, New York, 2015)

³⁴ Beijing Declaration on the Rights of People with Disabilities in the New Century available at: <http://www.dinf.ne.jp/doc/english/asia/conf/z00021/z0002101.html> (last accessed on April 01, 2019)

³⁵ 56th General Assembly Session, 10th November, 2001, available at: <https://www.un.org/documents/ga/docs/56/pv/a56pv44.pdf>, (last accessed on April 18, 2019) page 16.

³⁶ Whakanui Orang, *The New Zealand Disability Strategy: Making a World of Difference*, 2000, available at: <https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/nzds-easy-read.pdf> (Last accessed on April 18, 2022).

³⁷ General Assembly Resolution 56/168, available at: <https://www.un.org/esa/socdev/enable/disA56168e1.htm> (Last accessed on April 18, 2022).

³⁸ Chaired by New Zealand Ambassador Don MacKay, available at <https://www.un.org/press/en/2004/bio3597.doc.htm>, last accessed on 15 April, 2022

understanding with respect to the meaning and ambit of the terms and rights being advocated in the same sense.

The core themes that emerged while reading of the drafts in Ad Hoc Committee meetings were questions of legal capacity, institutionalization and forced interventions, inclusion or seclusion and issue of cross-disability action along with multiple vulnerabilities.

CRPD and Optional Protocol were adopted by the General Assembly by consensus. Years of lobbying by the disability activist for the Convention bore fruit and they had become agents and subjects of change. They convinced the national governments across the entire spectrum of United Nations to take their demands with utmost seriousness and negotiate with them as rights holders. Which led to 103 Members States ratifying the CRPD, and the same was entered into force on May 12, 2008.

Conclusion

Currently with promulgation of the CRPD, the first binding international documents acknowledging the rights of people with disabilities, the international disability policy has become a rights based policy. It introduced the intersection of the fields of international human rights law; disability law; right to health; developmental and disability studies and encompasses within itself all genres of disabilities and does away with the elimination of the distinction between positive and negative rights. Political and civil rights have been clubbed together along with social, economic and cultural rights in the overall structure of the convention.

To ensure compliance with the substantive provisions of the CRPD, the autonomy of state parties has been limited by prohibiting "reservations that are incompatible with the object and purpose of the Convention".³⁹ A unique monitoring and reporting mechanism has also been envisioned through the provisions of CRPD.

³⁹ *Supra* note 58 at art. 46