

Participation of Persons with Disabilities in Decision Making Process Concerning Their Interests

Abstract

This paper examines the International Law and Indian Law dealing with the Right of Participation by persons with disabilities in decision making process in matters concerning them. Traditionally persons with disabilities are denied this right. However now a days there is greater realisation by law makers and courts to treat them as capable of holding all the human rights and having the full legal capacity on an equal basis with others. They should necessarily be consulted in any matter concerning them and their views should be given proper weightage. In case of persons with intellectual disability, the idea of supported decision making in place of substitute decision making is preferred.

Keywords: Persons With Disabilities, Intellectual Disability, Mental Health, Substitute Decision Making, Supported Decision Making, Legal Capacity, Mental Capacity.



Anand Gupta
Assistant Professor,
School of Law
IGNOU, Maidan Garhi,
New Delhi, India

Introduction

There are mainly two approaches to deal with disability. Individual Approach and Social Approach.

According to Individual Approach, disability is treated as "individual pathology"¹. According to this approach, Disability results from the defect or Impairment present in the person. This approach treats Disability as a Medical issue and believes that Disability requires medical solution.

According to this approach, Persons with Disabilities are capable of holding rights² to a limited extent. They are mainly the (Objects) of rights not the (Subjects) of rights. As a result, they are not allowed to participate in decision making in matters concerning them. Due to this approach, till very recently, they were being provided with very little education including vocational education and training. They were considered to be capable of participating in economic, political, social, and cultural life of the society to a limited extent.

"Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives. Many have been presumed to be unable to live independently in their self-chosen communities. Support is either unavailable or tied to particular living arrangements, and community infrastructure is not universally designed. Resources are invested in institutions instead of in developing possibilities for persons with disabilities to live independently in the community. This has led to abandonment, dependence on family, institutionalization, isolation and segregation."³

The Social or Right Based approach treats Disability as a "Social Pathology"⁴. According to this approach, persons with disabilities are capable of holding all the Human Rights and entitled to exercise their choices. "... It means exercising freedom of choice and control over decisions affecting one's life with the maximum level of self-determination and interdependence within society. ..."⁵

Disability results not from the Defect or Impairment in the person but the Environmental and Situational factors. This approach positions disability as an important dimension of human culture, and it affirms that all human beings irrespective of their disabilities have certain rights which are inalienable. The specific needs of people with various disabilities should be taken into account while designing physical environment, services, facilities etc. In appropriate cases, he/she should be provided support in the form of guardianship or otherwise so that he/she can participate in decision making in matters which effect him/her directly or indirectly.

"Persons with disabilities still face significant attitudinal, physical, legal, economic, social and communication barriers to participate in public life. Before the entry into force of the Convention, the views of persons with disabilities were dismissed in favour of those of third-party representatives, such as organizations "for" persons with disabilities.^{6"}

Objectives of the Study

The objectives of this paper are:

1. Analyse the provisions of the UN Convention on the Rights of Persons with Disabilities, 2006 and the General Comments of its Monitoring Committee on the right to participate in decision making by persons with disabilities;
2. Examine the Indian Law including the court decisions on the topic;
3. Discuss the significance of involvement of persons with disabilities in decision making;
4. Offer suggestions as to how their involvement can be ensured in this matter.

UNCRPD

The Convention on the Rights of Persons with Disabilities (UNCRPD, 2006)⁷ contains "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" and "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity" as some of the guiding Principles. It affirms that all persons with disabilities have full legal capacity. It mandates states to provide persons with disabilities with access to support in the exercise of their legal capacity. Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making.

The UNCRPD⁸ recognizes the equal right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control their lives. The foundation of the article is the core human rights principle that all human beings are born equal in dignity and rights and all life is of equal worth.

Legal Capacity and Mental Capacity

"Legal capacity and mental capacity are distinct concepts"⁹. "Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). ... Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity"¹⁰.

"All persons with disabilities, including those with physical, mental, intellectual or sensory impairments, can be affected by denial of legal capacity and substitute decision making. However, persons with cognitive or psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity"¹¹.

The rights based model of disability implies a shift from the substitute decision-making to one that is based on supported decision making.

It may be noted here that The RPD Act, under section 14 introduces the concept of Limited Guardianship¹² in place of plenary guardianship. It provides that where a district court or any designated authority finds that a persons with disability who had been provided adequate and appropriate support but is unable to take legally binding decision may be provided further support of a limited guardian to take legally binding decisions on his behalf in consultation with such person in such manner as prescribed by the state government. Every guardian appointed for a person with disability shall be deemed to function as a limited guardian. In limited guardianship system, decisions are taken jointly by the guardian and the persons with disabilities.

The Supreme Court has recognised the right of mentally disabled persons especially persons with mild and moderate Mental Retardation to exercise their choice in their matters. However, the court has given protection in cases where their supposed capacity to give consent has been used to exploit them.

In *Suchita Srivastava v. Chandigarh Administration*¹³ the Supreme Court gave recognition to the legal capacity of a mentally disabled girl to continue her pregnancy. It was held in this case that since the victim had clearly expressed her willingness to bear a child. Her reproductive choice should be respected in spite of other factors such as the lack of understanding of the sexual Act as well as apprehensions about her capacity to carry the pregnancy to its full term and the assumption of maternal responsibilities thereafter.

The court observed, "There is no doubt that a woman's right to make reproductive choices is also a dimension of 'personal liberty' as understood under Article 21 of the Constitution of India. It is important to recognise that reproductive choices can be exercised to procreate as well as to abstain from procreating. The crucial consideration is that a woman's right to privacy, dignity and bodily integrity should be respected. Taken to their logical conclusion, reproductive rights include a woman's entitlement to carry a pregnancy to its full term, to give birth and to subsequently raise children even if it involves financial cost."

However, in *Tulshidas Kanolkar v. State of Goa*¹⁴ the court held that the consent of a intellectually disabled woman should not easily inferred in cases of rape. In this case, The parents of the victim noticed signs of advanced pregnancy in their daughter and it was only upon making enquiries with her at that stage that they were able to find out what had transpired. The girl had pointed at the appellant when asked questions about the incident. An FIR was lodged by the parents several months after the incident. A still born child was born to the victim. The accused was charge sheeted for offences punishable under sections 376 and 506(2) of the Indian Penal Code, 1860.

The Supreme Court held, "The plea of consent is too shallow to even need detailed analysis or consideration. A mentally challenged girl cannot legally

give consent that would necessarily involve understanding the implication of such consent.”

RPD Act

RPD Act¹⁵ cast upon the duty on the state to ensure that all children with disabilities have right on an equal basis to freely express their views on all matters affecting them and provide them appropriate support keeping in view their age and disability”. Similarly Section 13 (2) of the Act mandates government to ensure that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and have the right to equal recognition everywhere as any other person before the law.

The Act¹⁶ guarantees that persons with disabilities have access to appropriate information regarding reproductive and family planning. It also prohibits subjecting them to any medical procedure which leads to infertility without their free and informed consent.

The Act further prohibits medical or scientific experiments without the consent of the person concerned¹⁷. Such consent must be obtained through accessible modes, means and formats of communication and prior permission of a Committee for Research on Disability constituted for the purpose in which not less than half of the Members must be either persons with disabilities or Members of the registered organisation.

The Act¹⁸ mandates inter alia to Recognise the skills, merits and abilities of persons with disabilities and foster respect for the decision made by them on all matters related to family life, relationship, bearing and raising children.

Mental Health Care Act

The Mental Health Care Act, 2017¹⁹ deals with the rights regarding making choices during mental care. The Act provides that every person, including a person with mental illness shall be deemed to have capacity to make decisions regarding his mental healthcare or treatment if such person has ability to—

1. Understand the information that is relevant to take a decision on the treatment or admission or personal assistance;
2. Appreciate any reasonably foreseeable consequence of a decision or lack of decision on the treatment or admission or personal assistance;
3. Communicate the decision by means of speech, expression, gesture or any other means.

The Act further provides to every person who is not a minor, a right to make an advance directive in writing, specifying certain matters. An advance directive shall be invoked only when such person ceases to have capacity to make mental healthcare or treatment decisions and shall remain effective until such person regains capacity to make mental healthcare or treatment decisions.

Section 9 of the Act however provides that the advance directive shall not apply to the emergency treatment given to a person who made the advance directive. The matters on which the advance directives can be made are:

1. the way the person wishes to be cared or not to be cared for and treated for a mental illness;

2. The individual or individuals, in order of precedence, he wants to appoint as his nominated representative;

With regard to minor, Section 11 (4) provides that The legal guardian shall have right to make an advance directive in writing in respect of a minor till such time he attains majority.

Right of Choice in Education and Employment

“The active and informed participation of everyone in decisions that affect their lives and rights is consistent with the human rights-based approach in public decision-making processes, and ensures good governance and social accountability.”²⁰

In *Anka Toppo v. AIIMS*²¹ The complainant was denied to take the examinations for MBBS final year on losing sight by the All India Institute of Medical Sciences (AIIMS) on the ground that in view of the severe visual loss, it would not be possible for him to work in the medical profession.’ After great persuasion by the NHRC and on exposing the Respondent to numerous examples of blind people successfully pursuing medical profession, the Respondent finally agreed to take steps to examine him for the MBBS course by offering a modified methodology of examination. The NHRC expressed the view that the Medical Council of India should perform a similar exercise so that the same facility and system be available in other medical institutions also.

In *Umesh Kumar v. State of Haryana and Others* the court directed the college to admit to the engineering course a student whose vision could be corrected to the prescribed standard with the aid of glasses or contact lenses. The court observed:

“We live in the scientifically advanced age. If with medical aids particularly by provision of glasses or contact lenses the vision can be corrected to the standard prescribed, there is no reason why the candidate with the vision so corrected should be denied to the Engineering course. No reason has been assigned by the respondent as to why a candidate with power glasses above to 2.5 power be denied admission to Engineering course when such power glasses correct the defective reason up to the require standard.”

In *Amita v. Union of India*²² pursuant to an advertisement by the banking services recruitment board (BSRB) for the post of Probationary officer, a visually disabled lady, applied for the post. Her application was returned stating that the bank did not recruit blind candidate for the post.

The court held that the order pass by the board rejecting the application of the petitioner on the ground of disability was ultra vires to the Constitution. The petitioner satisfied the requirement asked for by the board for the post.

The court noted the technological development such as access technology which enable the blind persons to use computer as an effective tool for reading hard copy printed text to create and edit document brows the web and send mail etc independently.

Although these judgements are not pronounced on the right to participate in matters

concerning persons with disabilities, in these cases, the participation of persons with disabilities while taking decision is negligible. Their views about their capabilities and technological advancement was disregarded. They got relief only by the intervention of court and NHRC.

Conclusion

From the above analysis, it is clear that there is greater realisation in law makers and judges to respect the wishes of persons with disabilities including persons with intellectual disabilities which affect them although there are certain gray areas where there are difference of opinion as to what extent this right should be made available. A woman with mild or moderate mental disability can decide about the continuation of pregnancy. However in cases of offences such as rape etc, the consent should not be easily inferred. Every person with disabilities enjoys the legal capacity on an equal basis with others. The law makes a clear distinction between Legal Capacity and Mental Capacity. Mental capacity signifies the capacity of decision making which is influenced by various social and environmental factors. It has nothing to do with legal capacity. The idea of Supported Decision Making is preferred over the Substitute Decision Making. In supported decision making, all the relevant information is provided and decision is taken in consultation with the person. The person is provided all the support including limited guardianship so that he/she can exercise his/her choice. A person receiving mental care also can issue Advance Directives on certain matters to ensure that his/her wishes are regarded during treatment. The support services provided to persons with disabilities to discharge their rights should also be in conformity with the principles of Autonomy and Dignity.

It is however noticeable that the application of Best Interest Principle is the paramount consideration. The wishes of persons having intellectual disability may be disregarded if it is not in their interest. However it should not be used as pretext to disrespect his/her choices. Factor which needs to be taken into consideration is the level of maturity of the person concern. Wishes of the child who is in his/her teens and person with mild and moderate level of disability has more say in there matters as compared to a small child and person having severe mental illness.

Persons having no intellectual disability also at times also face difficulty in exercising their choices. There have been cases where they were not allowed to take admission in courses of their choice. They have also been denied employment opportunities in their chosen careers. They have not been involved while taking such decisions. Their views about the capability to pursue the course and do the job in questions were not been considered. Rather in majority of cases they were not even consulted. Such decisions are taken by the educational institutions, employers and authorities without involvement of persons with disabilities and their organisations. In some of such cases, the courts have passed favourable directions for persons with disabilities. It is suggested here that there should be inbuilt mechanism to ensure that persons with disabilities and their organisations be consulted and their views should be given due weightage before taking any decision on these matters. The list of identified jobs should be updated regularly in consultation with all the stakeholders. In appropriate cases, they should be allowed to work even in those jobs which are not

identified for them if they can prove their capacity to perform those jobs.

Law alone cannot ensure the availability of the right. Parents, guardians, professionals and social workers should be sensitised about the rights and capacities of persons with disabilities to form opinion about the matter concerning their interests. As stated in the introduction of this paper, disability should be treated as social issue rather than a medical issue only. Rights based approach should be adopted in dealing with disability issues. The UN body monitoring the CRPD has also taken this view:

"States parties should acknowledge the positive impact on decision-making processes and the necessity of involving and ensuring the participation of persons with disabilities, through their representative organizations, in such processes, notably because of their lived experiences and knowledge of the rights to be implemented. ..."²³

Endnotes

1. See generally *National Human Rights Commission Disability Manual*, (2005) pp. 18-19.
2. *ibid* pp. 17-18.
3. *Committee on the Rights of Persons with Disabilities General Comment no. 5 2017 on living independently and being included in the community para 1.*
4. *Supra* note 1 pp. 19-20.
5. *Supra* note 3 para 8.
6. *Committee on the Rights of Persons with Disabilities General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention para 5.*
7. *Convention on the Rights of Persons with Disabilities, 2006 Article 3 and 12.*
8. *Ibid* Article 19.
9. *ibid* para 13
10. *ibid* para 15
11. *Committee on the Rights of Persons with Disabilities General comment No. 1 (2014) on Equal recognition before the law Article 12 para 11.*
12. *Rights of Persons with Disabilities Act, 2016 Explanation to Section 14 (1), "a system of joint decision which operates on mutual understanding and trust between the guardian and the person with disability, which shall be limited to a specific period and for specific decision and situation and shall operate in accordance to the will of the person with disability."*
13. *AIR 2010 SC 235.*
14. *AIR 2004 SC 978.*
15. *Supra* note 12 Section 4 (2)
16. *Supra* note 12 Section 10
17. *Convention on the rights of persons with disabilities, 2006, Article 15, Rights of persons with disabilities Act, 2016 Sec-6*
18. *Supra* note 10 section 39.
19. *Mental Health Care Act, 2017 Ss 4,5 & 9*
20. *Supra* note 6 para 2.
21. *No. 1754/30/2000-2001 available at NHRC.nic.in/disparhive.asp.*
22. *Manu/SC/0481/2005.*
23. *Supra* note 6 para 9.