



# DISABILITY, LEGAL CAPACITY, RIGHTS.

## *Unpacking decision-making experiences of persons with multiple and psychosocial disabilities in India*

### LEGAL CAPACITY — THE RIGHT TO MAKE DECISIONS ABOUT ONE'S LIFE

**T**he right to make decisions is critical for all people. It allows individuals to make choices about how they live their lives, discover their identities, and exercise control over their engagement with society. In addition to being fundamental to individuals' self-determination, decision-making is a key component of consent or agreement by individuals to accept health and social services, to engage in sex and/or reproduction, and to enter into marriage, among other things. In fact, the ability and opportunity to make one's own decisions influences every aspect of life.

The right to make decisions that are recognized by law means the individual has "legal capacity". Legal capacity is the recognition of an individual's ability to make decisions that legally impact and shape their lives, such as to sign contracts, establish bank accounts, and make decisions about where and how they live, among others. Legal capacity and the

right to make independent decisions according to one's own preferences are fundamental to the exercise of human rights. Without legal capacity, individuals' actions and decisions do not have legal force and are not respected or validated by others. As a result, others (often family members and caregivers) tend to make decisions on their behalf.

In many contexts, persons with disabilities are not recognized as having legal capacity and are denied the right to make their own decisions. This denial is widespread, in part, due to misunderstanding and discriminatory attitudes and stereotypes around disability, gender, race, class, caste, age, and sexuality.

Laws and policies in many countries also deny the agency and decisional autonomy of persons with disabilities based on presumptions around disabilities, and specifically the perceived inability of persons with disabilities to make decisions, particularly among persons with multiple and psychosocial disabilities. These individuals suffer deprivations of their individual decision-making either informally or formally every day – at the hands of their families, partners, caretakers, and institutions.

Over-protection, speaking for and on behalf of persons with disabilities, and denying them the right to make their own decisions is a deeply rooted practice around the world and, in many cases, becomes embedded within families and communities. While families may not have malicious intentions, their actions can be harmful and deny individuals with disabilities their right to make individual decisions and navigate their own lives on their own terms.

This issue, while being central to disability rights movements, is often overlooked in feminist movements and across movements. If social justice movements are going to embrace disability rights and justice as central themes in organizing – a necessity for inclusive movement building – they must critically engage around key issues such as legal capacity, particularly as it relates to disability, gender and sexuality. This cross-movement work is crucial and aligned with past feminist initiatives where advocacy for independent decision-making featured prominently within the fights for economic status, voting rights, land ownership, and sexuality, among other things. The aim of this briefing paper is to unpack why engaging with legal capacity – both as it relates to laws and regulations and within informal practice – is key for cross-movement solidarity.

### EXPERIENCE OF PERSONS WITH MULTIPLE AND PSYCHOSOCIAL DISABILITIES IN INDIA: A CASE STUDY

In 2019-2020, Jeeja Ghosh, a gender and disability rights activist, undertook qualitative research in India with the support of CREA, focusing on the experiences around decision-making of persons with multiple and psychosocial disabilities. The research analyzed how legal capacity and decision-making were both formally and informally regulated by families or caregivers<sup>1</sup>. The research was based on 20 individual in-depth interviews with neurodiverse persons including on autism spectrum, persons with cerebral palsy, persons with psychosocial disabilities, as well as their support persons in India.

### WHAT IS LEGAL CAPACITY?

The ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency).

### WHAT IS SUBSTITUTE DECISION-MAKING?

Systems that allow others to make legally binding decisions about the lives and realities of persons with disabilities.

### WHAT IS INFORMAL SUBSTITUTE DECISION-MAKING?

When a person other than the individual with the disability is permitted to make decisions on their behalf without any legal authorization to do so.

### WHAT ARE GUARDIANSHIP AND CONSERVATORSHIP?

Types of substitute decision-making systems. When individuals are considered incapable of making their own decisions, guardianships and conservatorships may be sought to legally appoint another to make decisions on their behalf. Guardianships often apply to day-to-day decisions and conservatorships often apply to financial decisions.

### WHAT IS SUPPORTED DECISION-MAKING?

To support an individual with a disability to make decisions in a manner that is non-directive and where the individual remains the ultimate decision-maker.

Interviews were conducted via the Internet using audio-video communicators and the interviewers engaged with members of the disability rights movement in India and abroad, and their families or caregivers. The interviewees were between 18 and 50 years old, and primarily lived in urban areas in community settings. None of the interviewees lived in an institution or were formally deprived of their legal capacity. All interviewees had high levels of education and were working in the disability sector.

The research considered the particular experiences of four disability groups whose legal capacity often comes under scrutiny due to the nature of their conditions and perceived incapacities. Notably, persons with autism, cerebral palsy, psychosocial disabilities, persons with multiple disabilities, and persons who are non-verbal or have speech disabilities, are at greater risk of being placed under guardianship<sup>2</sup>. Women with disabilities within these five groups are even more likely to be denied decision-making either formally or informally<sup>3</sup>. Decisions are often made for these individuals by others based on the assumption that they are not competent or intelligent and that they lack the capacity to make decisions or from a paternalistic notion that they would not make the “right” decisions. Structural inequalities exacerbate existing perceptions regarding who can consent and make decisions about their bodies and lives.

Overall, the research revealed the myriad ways that the decision-making capacity of persons with multiple and psychosocial disabilities – even those who work as disability rights activists and human rights defenders – was denied. From everyday decisions about what to wear, what to eat, and even what books to read, to more significant decisions about consenting to

medical or psychological treatment, sexual activity and reproduction, finances, and property ownership and inheritance, persons with multiple and psychosocial disabilities were often deemed incapable of exercising agency in their own lives.

The interviewees shared their experiences of these deprivations, as well as the importance of having opportunities to develop decision-making skills to exercise their autonomy and choice. Through the interviews, persons with multiple and psychosocial disabilities and caretakers articulated that to learn how to make decisions and provide consent, individuals must be given the chance to make their own decisions, as well as to determine how and when to ask for help or support when needed. Rather, overprotection and denying individuals with disabilities of this type of experiential learning deprives them of important opportunities to gain essential decision-making skills and to determine their own lives.

### KEY RESEARCH INSIGHTS

**There is a widespread presumption that persons with disabilities do not know what is best for them and do not have the capacity to make their own decisions.**

This belief is implicated in all aspects of their lives and reflected in social norms, systems and services. One disability rights activist explained<sup>4</sup>:

*“In cases of persons with disabilities, the presumption of incapacity begins from the moment the diagnosis of disability is imposed on them. This assumption of incapacity is reflected throughout the socialization process. Thus, for children with disabilities, this underlying presumption that they cannot build their capacities or make decisions for themselves in the same way as their non-disabled peers is implicated in all aspects of their lives – from the education they are imparted to the way family members and neighbors interact with them.*

To move a step further, as persons with disabilities are not expected to make decisions about their lives, the

<sup>1</sup> Complications of the COVID-19 pandemic shaped the interview process and pool of interviewees.

<sup>2</sup> See, e.g., Hans, A., and Kannabiran, K., Introduction, Council of Social Development, INDIA: SOCIAL DEVELOPMENT REPORT – DISABILITY RIGHTS PERSPECTIVES, edited by Kalpana Kannabiran and Asha Hans 2016, <http://www.csdhyd.org/Publications/India%20Social%20Development%20Report%202016.pdf#page=203> [hereinafter INDIA: SOCIAL DEVELOPMENT REPORT-2016]; see also Hans, A., Accessing Rights Women with Disabilities, in INDIA: SOCIAL DEVELOPMENT REPORT - 2016.

<sup>3</sup> Nayar, M. and Mehrotra, N., Invisible People, Invisible Violence Lives of Women with Intellectual and Psycho-social Disabilities, in INDIA: SOCIAL DEVELOPMENT REPORT – 2016.

<sup>4</sup> All names and associations of the interviewees in this research have been kept anonymous to protect their confidentiality.

liberty of making choices is mostly unavailable to them. Closely linked to this is the notion that they are in need of being “protected” or “cushioned” from making mistakes. . . . This in turn deprives them from learning from their live experiences which often serve as the tools for decision-making”.

Another interviewee with cerebral palsy and speech impairment explained that despite being educated, she was overprotected and denied the opportunity to make basic decisions about what to eat and when because she was physically reliant on her family. She expressed that:

*“It’s ridiculous and that actually depresses [me] because . . . [ I am] not able to go and buy [food,] so [I] get so depressed that it reduces [my] urge to live at all. [I] feel that if everything in my life is decided by others then why should I live?”*

**Once labeled as having a disability, professionals, caregivers, and families often assume that the individuals are incapable of making decisions and there is limited investment in learning the different ways to support them in making their own choices.**

A woman who is a prominent feminist disability activist with a psychosocial disability explains:

*“This incapacity mess is something that plagues people right from the time that they acquire the disability, whether it’s at birth or it’s later on, and when a diagnosis is accompanied by the incapacity certification, so to speak, because they usually come from medical professionals or other professionals so their entire trajectory changes because you are like, okay . . . this person would never make decisions so why should we train them on that and it’s true to say that, yes, we need to give tools to people to make decisions which include making these decisions accessible to them.”*

**Persons with disabilities are considered incompetent and incapable of making decisions about their health and reliance on medication.**

An interviewee was diagnosed with bipolar disorder in her teens. She was subsequently prescribed psychiatric medication which could invoke suicidal tendencies

without being informed of those risks. She became suicidal at one point and was then deemed unfit to perform her job. The interviewee explained that had she been warned about the consequences of the medication she could have decided not to take it or avoided stressful situations which could have made her vulnerable to suicidal thoughts.

By contrast, another interviewee with cerebral palsy who uses a wheelchair and has a speech impairment described that given her restricted mobility she had a small social circle which led her to feel lonely and depressed. She started attending group therapy and seeing a psychiatrist who suggested she start taking a low-dose antidepressant. She explained:

*“When I told my mother she objected. She is somewhat orthodox regarding any form of medication. In fact, my mother refused to give me even a painkiller when I was in great pain because of my increasing scoliosis. My mental health subsequently took a toll on my physical health.”*

**Overprotection and control are persistent within the home.**

One disability rights activist explained that the level of control in the homes of persons with disabilities is akin to being in an institution. She explained:

*“Institutions are a state of mind, institutions are not just a physical structure so somebody who is not given any agency to decide what they want to do, what they want to eat, you know . . . when they would like to do certain things and when everything is decided by someone else, it is living in an institution even if they are living in their homes with loving parents and families...”*

Institutionalization is one mechanism in which persons with disabilities are denied their decisional and bodily autonomy. To this end, advocating for the right to live independently and be included in the community, as guaranteed by Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD)<sup>5</sup> is a key strategy of the disability rights movement.

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<sup>5</sup> UN Convention on the Rights of Persons with Disabilities, <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>.

Overprotection of parents and caregivers erodes the possibility for a person with a disability to have agency and self-determination.

One caregiver explained:

*“When parents make decisions for persons with disabilities all their lives, and they are dependent on us all their lives and when we are not there then they will be nothing, yes . . . the truth is that because you are not teaching them anything, because you are not supporting them to take their decisions. When you are not there then they will be nothing, and that’s not because they have an impairment, it’s because they are not taught, they have not been exposed to decision-making and independence.”*

#### WHY IS LEGAL CAPACITY A FEMINIST AND CROSS-MOVEMENT ISSUE?

Autonomy and independent decision-making are issues that are central to feminist movements and across movements. Yet, everyday individuals with multiple and psychosocial disabilities are formally or informally denied the ability to make independent decisions, which has specific impacts on their health, well-being, and lives. These denials also impede the exercise of their human rights, including their sexual and reproductive health and rights (SRHR) such as bodily autonomy, consensual decision-making around relationships, sex, intimacy, and expressing their gender, sexuality, and identities<sup>6</sup>.

Legal capacity and supported decision-making are also essential to feminist principles of bodily autonomy, consent, and reproductive justice. Ensuring legal capacity gives persons with disabilities the power to make decisions, which is essential to achieving gender equality and central to individuals’ well-being and empowerment<sup>7</sup>. Significantly, women and girls with disabilities experience particularly higher rates of sexual and gender-based violence and forced and coerced sterilization, contraception, and other forced medical and psychiatric treatments. The ability to consent to sex and access pleasure, to make informed decisions about one’s healthcare and treatment, as well as exercise

freedom and control over one’s life, is also essential to the dignity and human rights of all people with disabilities.

Independent decision-making, including supported decision-making, empowers persons with disabilities, as well as centers their choices and preferences. In contrast, to substitute decision-making, supported decision-making seeks to enable individuals to make consensual choices, not forced or coerced decisions or decisions made without informed consent. This can be facilitated by providing information in plain language and various formats, allowing extra time to make decisions, ensuring that the individual fully understands their options, accompaniment, and other forms of support can enable persons with disabilities to exercise their agency.

#### WHAT DOES HUMAN RIGHTS LAW HAVE TO SAY?

The CRPD introduced universal legal capacity which cannot be limited on the grounds of disability in Article 12 (Equal Recognition before the Law). Significantly, equal recognition before the law marks a distinct shift in paradigm in which all persons with disabilities are rights holders and can exercise their rights according to their own will and preferences. The Convention also makes provision for support needed for decision-making to exercise one’s legal capacity through strategies such as reasonable accommodation and supported decision-making. The other critical shift that is central to Article 12, as maintained by the CRPD Committee, is that it ends substitute decision-making regimes such as guardianship or conservatorship<sup>8</sup>.

<sup>6</sup> In addition to being denied autonomy in everyday decision-making, women and girls with disabilities have been subjected to non-consensual, forced sterilization, hysterectomies, and abortions. See CRPD Committee, General Comment 3: Article 6: Women and girls with disabilities, para. 51, UN Doc. CRPD/C/GC/3, 2016; Human Rights Watch, Sterilization of Women and Girls with Disabilities: A Briefing Paper, 2011, <https://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities>.

<sup>7</sup> Arstein-Kerslake, Anna, Vulnerability Created by Barriers to Legal Capacity for Women and Disabled Women, *INTERNATIONAL JOURNAL OF LAW AND PSYCHIATRY*, Vol. 66, September-October, 2019.

<sup>8</sup> This interpretation of Article 12 is contested by many in literature and policy review, but for the majority of disability activists, this is central to goals of independent living, ending institutionalization and segregation, as well as to ending forced treatments and fundamental rights of citizenship such as owning property, having a bank account and making a choice to be in a relationship.

## LEGAL FRAMEWORKS IN INDIA

State signatories to the CRPD are legally obligated to align their disability legislation with the principles of the convention. As such, India enacted two progressive pieces of legislation – the Rights of Persons with Disabilities Act<sup>9</sup> and the Mental Healthcare Act<sup>10</sup>. Both laws were underpinned by key rights enshrined in the CRPD.

The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, adopted by the Indian government in 1999, however, still remains in force. This law presumes that persons with autism, cerebral palsy, and intellectual disabilities lack legal capacity and calls for substituted decision-making through a guardianship regime. Significantly, the National Trust Act is in contrast to the 2016 Rights of Persons with Disabilities Act which calls for supported decision-making.

Despite the overall shift in legislation towards the right to legal capacity for persons with disabilities on an equal basis and the right to equal recognition before the law<sup>11</sup>, exercising these rights in practice still remains out of reach for many individuals with disabilities. The laws also have contradictions and fail to put in place the systems needed to truly implement supported decision-making.

## CONCLUSION

Care and support are not simply a disability rights and justice issue, but essential for all people at all stages of life. However, these issues are particularly important for persons with disabilities. Care and support alone are not enough to ensure the rights of persons with disabilities to live on their own terms. Care and support must be offered, whether by family members, friends, caregivers, or communities, in an affirmative way that does not limit or deny the decision making of persons with disabilities, but

rather provides them the space to exercise decisional autonomy, make mistakes, and to learn in the process.

Relying on others for support in decision-making can be particularly challenging for persons with disabilities as they transition from childhood to adulthood. Notions of parenting and support provision can become conflated and, in turn, lead parents and/or caregivers to fail to allow for increasing independence in decision making over time, as the individual with a disability matures over time. Given this reality, many individuals interviewed for this research emphasized the importance of allowing persons with disabilities to develop decision-making skills, including by permitting them to make mistakes and learn from the consequences and by enabling them to develop relationships with people they trust to support them in navigating decisions.

Progress towards ensuring recognition of the legal capacity of individuals with disabilities and enabling the exercise their human rights, including their SRHR, requires conceptualizing and providing care and support in a non-patriarchal and mindful manner that accounts for the capacity and individuality of persons with disabilities. Taking these steps would enable individuals with disabilities to engage in independent decision-making with support if needed, all of which aligns with feminist and human rights principles of autonomy, equality, equity, and justice.

<sup>9</sup> Rights of Persons with Disabilities Act, 2016, <https://www.indiacode.nic.in/bitstream/123456789/2155/1/a2016-49.pdf>.

<sup>10</sup> Mental Healthcare Act, 2017, <https://www.indiacode.nic.in/bitstream/123456789/2249/1/A2017-10.pdf>

<sup>11</sup> The Rights of Persons with Disabilities Act, 2016, 13: Legal Capacity. While the law provides equal recognition as persons before the law, it does not explicitly stop or prohibit substitute decision-making and makes provisions for limited guardianship.



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