

# Understanding Legal Guardianship for Persons with Intellectual and Developmental Disabilities

An Exploratory Study from  
a Socio-Legal Lens



## Acknowledgments

This report carries the effort of several people and friends of Pacta. This report was authored by Dishari Chakrabarti (Lead, Legal and Operations, Pacta) and Krithika Sambasivan (Lead, Disability Research, Pacta) under the guidance of Nivedita Krishna (Founder-Director, Pacta) and Jeeja Ghosh (Manager, EnAble India).

The Report is designed by Sudeshna Bose (Graphic Designer, Pacta) with editorial support from Susan Job (Communications Associate, Pacta) and illustration contributions from Samarth (Consultant Artist) .

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**Suggested Citation:** Understanding Legal Guardianship for Persons with Intellectual and Developmental Disabilities: An Exploratory Study from a Socio-Legal Lens. Pacta and EnAble India, Bengaluru, December 2024.

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## A Note of Thanks

Pacta thanks Jeeja Ghosh for bringing to light the issue of legal guardianship for persons with intellectual and developmental disabilities. We thank EnAble India for the opportunity and funding for this project.

The researchers thank and acknowledge the contribution of all participants of the study including parents and persons with disabilities for their openness and willingness to discuss concepts of autonomy, legal capacity, and legal guardianship. We thank Mr. Alvito Barreto for organizing the 2 focus group discussions (FGDs) with parents in Bangalore. We thank Dr. Aruna and Tamahar Trust for willingly hosting these FGDs on their premises. We also thank Ms. Chaitali Gami for bringing together the virtual FGD with persons with disabilities in Kolkata.

We thank the experts who provided early thoughts and guidance on autonomy, decision-making capacity and legal guardianship through their experiences in the field - Dr. Kirthika Rajaraman (Developmental Pediatrician, CCDD, Bengaluru), Mr. Subhash Chandra Vashisth (Advocate and Founder, CAFE, India), Ms. Arathi Harish (Founder, Saadhya Trust), Dr. Soumitra Pathare (Director, Centre for Mental Health Law and Policy (CMHLP), Pune), and Mr. Arjun Kapoor (Program Manager and Research Fellow, CMHLP, Pune).

We acknowledge the research contributions of Manasvini Ranganathan (Associate Legal Policy, Pacta) and of interns - Varsha M. Ashok (KLE Law College, Bengaluru), Devika Krishnan and Navaneeta Manu (National University of Advanced Legal Studies, Kochi) who helped with secondary research on interpretations of legal capacity, decision-making capacity, and legal guardianship within the context of the Indian Laws, as well as on the extent of implementation of these laws.

We thank the Legal Collective of EnAble - Shanti Raghavan, Pratibha Nakil, Amar Jain, Nipun Malhotra, Reena Kuttan, Priti Lobo, and Nayi Disha team - Ankur Singh, Keshav Bishnoi, and Madhura for their time and feedback on the first round of presentation of the legal guardianship report and their vision for the next steps to channelize legal guardianship in India.

## Glossary of Terms

- 1. Autism Spectrum Disorder (ASD):** A developmental disorder characterized by difficulties in social interaction, communication, and repetitive behaviors
- 2. Cerebral Palsy (CP):** A group of disorders that affect movement and muscle tone or posture, caused by damage to the developing brain.
- 3. Consequential Decisions:** Decisions that have significant impact or consequences for the individual making the decision.
- 4. Decision-Making Capacity:** Decision-making capacity is the ability of a person to understand relevant information, appreciate the consequences of a decision or lack of decision, and communicate their decision.
- 5. Everyday Decisions:** Routine decisions that individuals make in their daily lives, such as what to wear or eat.
- 6. Individual Autonomy:** Individual autonomy is the right of individuals to make their own choices and decisions about their lives, free from undue influence or coercion. It is a fundamental principle in ethical and legal frameworks.
- 7. Intellectual Disability (ID):** A neurodevelopmental disorder characterized by limitations in intellectual functioning and adaptive behavior.
- 8. Legal Capacity:** Legal capacity refers to a person's right to make decisions that have legal consequences for themselves. Legal capacity gives the right to access the legal system and provides legal independence to speak on one's behalf.
- 9. Multiple Disabilities (MD):** A person with several different disabilities is said to have multiple disabilities. Examples of multiple disabilities include Deafblind (Visual Impairment + Hearing Impairment), Visual Impairment + Hearing Impairment + Mental Retardation, Visual Impairment + Mental Retardation or Cerebral Palsy + Mental Retardation/Hearing/ Speech/Visual problems.
- 10. Navigating Decisions:** The process of making decisions, particularly in complex or challenging situations, with the goal of reaching a satisfactory outcome.

## Glossary of Terms

- 11. Legal Guardianship:** Legal guardianship is a legal relationship between a competent adult (the guardian) and a person who lacks the capacity to make decisions (the ward). The guardian is granted authority to make decisions on behalf of the ward.
- 12. Limited Guardian/Guardianship:** Limited guardianship is a form of guardianship in which the guardian is granted authority to make only specific decisions on behalf of the ward, rather than all decisions. This is often used to preserve the individual's autonomy to the extent possible.
- 13. Smooth Transition:** The process of moving from one stage or state to another in a way that is gradual and without disruption.
- 14. Substituted Decision-Making:** Substituted decision-making is a legal process in which someone else is authorized to make decisions on behalf of a person who lacks the capacity to make those decisions themselves. This is often used when an individual is incapacitated or unable to make decisions due to a disability.
- 15. Supported Decision-Making:** Supported decision-making is a process in which individuals with disabilities are supported by one or more persons of their choosing to make decisions about their lives. The supporters help the individual understand the information relevant to the decision and communicate their decision.

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**Part 1**

**Introduction**

## 1. Introduction



Legal guardianship is afforded to those who require support in decision-making under the law. Legal guardians act on behalf of the person to make decisions and exercise their legal capacity. Legal capacity is presumed to be reduced when there is decreased decision-making capacity for those with disabilities. Therefore, in reality, persons with disabilities do not enjoy equal rights as those without disabilities.

Legal guardianship for persons with disabilities is governed under three major acts in India, namely the National Trust (NT) Act, 1999, the Rights of Persons with Disabilities (RPwD) Act, 2016 and the Mental Health (MH) Act, 2017. The NT Act and RPwD Act apply to those with Intellectual and Developmental Disabilities including Cerebral Palsy (CP), Autism Spectrum Disorder (ASD), Intellectual Disabilities (ID), and Multiple Disabilities (MD). RPwD Act was drafted after India ratified the The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007. The UNCRPD and RPwD Act recognize the legal capacity of all individuals under the law, and legal guardians are only afforded a limited capacity to act on behalf of persons with disabilities. However, the two Acts do not converge on processes or ideologies.

**Differences in the laws create implementation challenges and divide the socio-legal structures of legal guardianship for persons with disabilities envisaged under the RPwD Act and NT Act.** There is western literature on the interplay of legal capacity, decision-making capacity and legal guardianship from a legal and medico-legal lens, but there is little literature on this topic in the Indian context.

Therefore, this study aims to understand the dissonance between the current legal frameworks and practices associated with the appointment of guardians for persons with Cerebral Palsy, Autism Spectrum disorder, Intellectual Disability, and multiple disabilities i.e., disabilities covered under NT Act.

**In this paper, “persons with disabilities” predominantly refers to persons with CP, ASD, ID, and MD i.e., the disabilities covered under NT Act.**

## 1.2. Methodology



A qualitative research approach was employed for inquiry. In-depth interviews were conducted with 8 parents, 1 sibling guardian, 7 persons with disabilities, and 6 experts (a total of 22 interviews). Additionally, 3 Focus Group Discussions (FGDs) were organized: two with parents (one involving 3 parents and the other with 14-15 parents) and one FGD with persons with ASD and ID (involving 9 persons with disabilities). Details of the interview participants are provided in **See Annexure 1 & 2.**

All interviews were transcribed and coded, and respective themes were drawn based on the codes.



### 1.3. Summary of Findings



#### **Finding 1: On Social Influencers of Legal and Decision-Making Capacity**

Inner and outer circles of a person with disability shape their legal capacity and autonomy. There is an intricate relationship between parental-cultural attitudes, as well as socio-institutional structures, and the way they affect the legal capacity of persons with disabilities and, thus, their autonomy.

#### **Finding 2: On Legal Capacity**

Most parents, despite being well-educated and aware of multiple aspects of disabilities, did not fully understand the term ‘legal capacity’ and were unaware of the rights of their adult child. The same is true for those with disabilities. Unless there are conscious efforts to raise awareness and build capacity—whether a parent or a person with a disability themselves—a majority will remain marginalized.

#### **Finding 3: On Decision-Making Capacity**

Parents understand the term ‘decision-making’ in general and in the context of their children with disabilities, but do not allow room for decisions that may have negative consequences. Most parents determine and limit their child’s decision-making capacity based on their lived experiences while raising them. According to interviews and parent narratives, people with disabilities make smaller everyday decisions, while larger decisions regarding finances and property are made by the parents, particularly in cases of ID and ASD, regardless of the level of functioning.

#### **Finding 4: On Legal Guardianship**

There are variations in the practice of legal guardianship due to differing knowledge of decision-making capacity and legal capacity among parents, the community, and institutions regarding persons with disabilities. Awareness about legal guardianship is often murky. Parents take up legal guardianship across the wide range of decision-making capacity impairment of the person with disabilities.

#### **Finding 5: On Challenges Associated With the Surrounding Process of Legal Guardianship**

There are variations in the practice of legal guardianship due to differing knowledge of decision-making capacity and legal capacity among parents, the community, and institutions regarding persons with disabilities. Awareness about legal guardianship is often murky. Parents take up legal guardianship across the wide range of decision-making capacity impairment of the person with disabilities.

#### **Finding 6: On Other Parent Responses Towards Securing Their Children’s Future**

Concepts of group homes for children with intellectual and developmental disabilities are slowly coming up across the country. Parents, with or without formal guardianship, are proactively establishing private trusts to ensure their child’s financial stability in the long run.

#### **Finding 7: On Guardianship By Natural Life-Cycle**

During the years of transition from childhood to adulthood, parents lack awareness about legal guardianship processes and regarding the rights of persons with disabilities.



## 1.4. Recommendations

<b>Recommendation 1</b>	Consolidate guardianship laws towards a new comprehensive legal framework for legal guardianship aligned with the UNCRPD
<b>Recommendation 2</b>	Amend the NT Act aligned with the UNCRPD, enshrining principles of legal capacity for persons with disabilities.
<b>Recommendation 3</b>	Standardize adjudicating authority & processes for appointing legal guardian under RPwD Act
<b>Recommendation 4</b>	Drive compliance with accessibility provisions under RPwD Act to enable meaningful inclusion and decision-making for persons with disabilities
<b>Recommendation 5</b>	Abolish IQ as a barometer for decision-making capacity determination and disability certification
<b>Recommendation 6</b>	Conduct awareness programs to bridge gaps between intent of UNCRPD and lived realities of persons with disabilities
<b>Recommendation 7</b>	Make data about legal guardianship for persons with disabilities publicly available to facilitate research



**Part 2**

**Problem Statement**

## 2. Problem Statement



Under Indian law, legal capacity is presumed to be absent for persons of unsound mind, and the laws provide for a legal guardian who can supply that capacity. One law, the NT Act provides for legal guardians to act in substitution for their wards with disabilities, while RPwD Act provides for legal guardians to act only in a supportive capacity. This dissonance in law also spills into real life, where legal guardians often overreach their authority. This issue is further amplified because the NT Act is a preferred pathway for legal guardianship compared to the RPwD Act.

In this study, we explore the relationships between decision-making capacity, legal capacity, and legal guardianship through the lived experiences of adult persons with disabilities and their families. Furthermore, the study delves into the question of why the NT Act is preferred in legal guardianship matters over the RPwD Act.

**When we order food through platforms such as Swiggy or Zomato or book tickets on BookMyShow, we exercise legal capacity. Legal capacity is the ability to make legally binding decisions and have them recognised under the law.**

**Under the law, you and the service-providing platform have a contractual agreement that helps you exercise and uphold your rights. Legal capacity is fundamental to autonomy and personhood, allowing individuals to make choices and act on their own behalf.**

**Legal capacity underpins how we navigate daily life, from simple actions such as purchasing meals (paying money and buying food) to complex decisions about finances (opening a bank account) or healthcare (accepting or rejecting treatment).**

**The exercise of legal capacity depends on decision-making abilities, and the law typically presumes that individuals with a 'sound mind' have legal capacity. For persons with disabilities, especially those with intellectual disabilities, legal capacity exists as a human right in rights-based frameworks but is missing in their lived experiences.**



**Part 3**

**Legal Context of  
Guardianship for  
Persons with Disabilities**

### 3. Legal Context of Guardianship for Persons with Disabilities



Before we unpack the experiences of persons with disabilities and their guardians, it is important to clarify certain key concepts.

#### 3.1. Key Concepts



**Legal Capacity** refers to an individual's capacity to hold rights and exercise those rights, as recognized under the law. **Legal capacity** transforms a human being into a subject of law, recognizing them as a legal entity with rights, obligations, and the ability to make binding and enforceable decisions. This legal capacity underscores the individual's competence and autonomy in making legally binding choices.<sup>1</sup> The possession of legal capacity empowers individuals to make crucial choices that impact their lives, ranging from the momentous (such as selecting their place of residence and companions) to the routine (such as purchasing a bus ticket, signing a lease, or consenting to medical care). By extension, legal capacity facilitates personal freedom, enabling individuals to pursue employment, marry, inherit property, and exercise various other rights. Additionally, it safeguards individuals against certain unwanted interventions, empowering them, for instance, to refuse medical treatment they deem unsuitable.<sup>2</sup> The recognition of legal capacity aligns with Article 12 of the UNCRPD, which states that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."

**Decision-making fundamentally refers to the process of selecting from options to identify a decision, collecting information, and evaluating alternative resolutions.**

Buchanan and Brock categorize decisions into four key areas: healthcare, finances/property, living arrangements, and medical research participation.<sup>3</sup> The formal concept of decision-making capacity pertains to an individual's cognitive ability to make well-informed choices. The acknowledgment of **decision-making capacity** for all individuals is rooted in the principle of **individual autonomy**.<sup>4</sup> Autonomy, the ability to govern oneself, underpins informed decision-making. Individuals need access to relevant information, the ability to reflect on their values, desires, and goals, and the capacity to make intentional choices based on these reflections, effectively communicating them. The components and the processes of decision-making are described in **Box 1**.

<sup>1</sup>Council of Europe Commissioner for Human Rights. (2012, April). Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities. In <https://rm.coe.int/who-gets-to-decide-right-to-legal-capacity-for-persons-with-intellectu/16807bb0f9>.

<sup>2</sup>Watson, J. (2016, February 19). Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability. *Laws*, 5(1), 6. <https://doi.org/10.3390/laws5010006>

<sup>3</sup>Agarwal, & D'Souza. (2021, March). Decision Making for Persons with Impaired Capacity. In Vidhilegalpolicy.in . Retrieved July 31, 2023, from <https://vidhilegalpolicy.in/wp-content/uploads/2021/03/Decision-Making-for-Persons-with-Impaired-Capacity-Full.pdf>

### Box 1: Components of Decision-Making and Decision-Making Capacity

Decision-making capacity comprises six essential components.



**Understanding the pertinent information** related to a decision, encompassing its nature, context, and potential consequences, and entails processing, retaining, and recalling presented information.



**Analyzing received information**, contemplating alternative options, and assessing the potential benefits and drawbacks of each choice, involving critical thinking, risk evaluation, and logical conclusion formation.



The capability to **communicate one's decision clearly and effectively to others**, considering their needs and perspectives.<sup>5</sup>



Evaluating whether an individual's decision-making abilities remain **consistent over time**. This consideration ensures that temporary fluctuations or external influences do not compromise the validity of the decision.



**Recognizing the potential impact of external factors is crucial**. Coercion, undue influence, or cognitive impairments can significantly affect an individual's ability to make informed choices.



Ultimately, decision-making capacity hinges on the **ability to express a choice** regarding the decision at hand. This includes the capacity to say yes or no or to actively select among available options. This ensures that the chosen course of action reflects the individual's values and preferences.<sup>6</sup>

These processes form the core of self-determination, empowerment, and social inclusion for any individual, particularly for those with disabilities. decision-making are described in **Box 1**.

<sup>5</sup>India Mental Health Observatory (2021). Manual on Supported Decision-making - for caregivers. Centre for Mental Health Law and Policy. <https://cmhlp.org/wp-content/uploads/2021/11/Caregivers-Manual-on-Supported-Decison-Making.pdf>

<sup>6</sup>Gunn, WONG, Clare, & HOLLAND. (1999). Decision Making Capacity. Medical Law Review, 7, 269–306.

Decision-making approaches for persons with disabilities range from **supported decision-making**, where the individual retains ultimate authority with assistance, to **substituted decision-making**, where a surrogate acts on their behalf (described in **Box 2**).

### Box 2: Spectrum of Decision-Making

- **Substitute Decision-Making:** Systems that allow others to make legally binding decisions about the lives and realities of persons with disabilities.
- **Informal Substituted 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.
- **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.
- **Facilitated Decision-Making:** When the support person actively plays a role in guiding the decision of the person with a disability. This is rarely used and only when one has limited knowledge about a person with a disability. This form of decision-making seems to adopt the 'best interests' principle. This type of decision-making seems to be more along the lines of substituted decision-making rather than supported decision-making.



### 3.2. Guardianship



**For persons with disabilities (those with psychosocial impairments, developmental disabilities, or intellectual disabilities) and reduced decision-making capacity, the law offers a solution — “dependence” on a legal guardian to make decisions and exercise legal capacity on their behalf. disabilities, especially those with intellectual disabilities, legal capacity exists as a human right in rights-based frameworks but is missing in their lived experiences.**

**Under the legal context, Guardianship** denotes a **judicial process** whereby the State, upon determining an individual's **lack of capacity**, confers the legal authority to make and enact decisions upon another individual or entity, effectively **depriving the individual of their decision-making autonomy in specific areas or entirely**.<sup>7</sup>

Traditionally, the State, acting in its **parens patriae**<sup>8</sup> capacity, has been entrusted with the legal authority to intervene in the lives of adult individuals who, due to impaired cognitive or functional abilities, lack the capacity to make decisions for themselves. This intervention, aimed at safeguarding their welfare and well-being, has historically been implemented through the appointment of a **guardian**.<sup>9</sup> Guardians, acting on behalf of the individual, assume the responsibility of making decisions across various aspects of their lives.

However, guardianship orders raise crucial concerns, as they can potentially result in the **effective civil death** of the individual under the law. By stripping individuals of their decision-making autonomy, these orders can significantly impact their lives and curtail their fundamental rights.<sup>10</sup>

### 3.3. Key Laws on Guardianship, Legal Capacity and Decision-Making Capacity



#### **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2007**

The enactment of the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2007** served as a direct response to discriminatory legal **guardianship** systems that denied legal capacity and participation in public and private life to individuals with disabilities.

**As enshrined in the UNCRPD, the absence of spoken language does not negate the presence of meaningful thoughts, opinions, and desires within individuals with ID, Article 12 of the UNCRPD reinforces the principle of equal legal capacity for persons with disabilities, including those with ID.**<sup>11</sup>

<sup>7</sup>Glen, K. B. (2012). Changing paradigms: Mental capacity, legal capacity, guardianship, and beyond. *Columbia Human Rights Law Review*, 44, 98-169. [ets-to-decide-right-to-legal-capacity-for-persons-with-intellectu/16807bb0f9](https://doi.org/10.21203/rs.3.rs1881486/v1).

<sup>8</sup>English guardianship law embodied the concept of *parens patriae* which persists to this day. This concept began in 1290 with the enactment of *de Prerogative Regis*, which provided: “A king... as the political father and guardian of his kingdom, has the protection of all his subjects, and their land and goods, and he is bound, in a more peculiar manner, to take care of those who, by reason of their imbecility or want of understanding, are incapable of taking care of themselves.”

[ps://doi.org/10.3390/laws5010006](https://doi.org/10.3390/laws5010006)

<sup>9</sup>3Cantor, N. (2005). The bane of surrogate decision-making: Defining the best interests of never-competent persons. *Journal of Legal Medicine*, 26, 155.

<sup>10</sup>Supra 13

<sup>11</sup>Article 12(2) of the UNCRPD specifies that State Parties recognise the legal capacity of persons with disabilities on an equal basis in all aspects of life. Paragraphs 3 and 4 of the same Article further oblige State Parties to provide “support” to persons with disabilities to exercise their legal capacity and ensure that no abuse occurs in the process.

Though it is a significant step forward in strengthening the rights of persons with disabilities, the implementation of supported decisions as envisaged under the UNCRPD remains mired in challenges (**Box 3**).

### **Box 3: Concerns with the implementation of the UNCRPD's principles on facilitating autonomy**

While the UNCRPD represents a significant step forward for disability rights, its implementation remains complex.

- One key concern is the potential **conflation of "legal capacity" and "decision-making capacity"**. These concepts have distinct meanings. Legal capacity refers to the recognition of an individual's actions in the legal system, while **decision-making capacity** encompasses the mental ability to make decisions. Buchanan & Brock (1986) point out that conflating them can lead to unimplementable legal and policy approaches, potentially undermining the rights and freedoms individuals are meant to enjoy. But the fact remains that several legal systems (especially the Indian legal system) have conflated the concepts resulting in depriving legal capacity for persons with reduced/impaired decision-making capacity - **see Annexure 3**
- The UNCRPD's emphasis on **supported decision-making** as the primary approach dangerously implies that everyone can be supported to make their own choices, regardless of their level of decision-making ability. However, Parker argues that this may not be feasible in cases where individuals lack complete decision-making capacity. Over-estimating capacity in such situations could lead to harm, as supported decisions may not truly reflect their autonomy.
- There is a dearth of research and resulting toolkits illustrating how supported decision-making can go from theory to practice, in various contexts — everyday decisions, medical/health, data privacy, employment, financial, immovable property, etc. Culturally paternalistic practices are backed by paternalistic laws, where a caregiver makes broad-based decisions for the person with a constrained decision-making capacity. This means that local laws as well as practices should change. The question then beckons - which should change first - law or practice?

<sup>12</sup>Parker, M. (2016). Getting the balance right: Conceptual considerations concerning legal capacity and supported decision-making. *Bioethical Inquiry*, 13(3), 381–393

<sup>13</sup> Ibid

### 3.4. Laws in India



In India, the legal framework governing capacity and decision-making presents a complex and fragmented picture. Unlike some countries with unified approaches, India relies on a patchwork of population-specific laws alongside the general legal framework.

**Article 12(2)** of UNCRPD says that “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”. So the legal capacity of persons with disabilities is vested in the fundamental right to equality under the Constitution. **Article 14** of the Indian Constitution confers the right to equality and equal protection before the law for every citizen.

**National Trust (NT) Act, 1999, the Mental Healthcare (MH) Act, 2017, and the Rights of Persons with Disabilities Act, 2016 (RPwD Act)** address decision-making and capacity for defined populations. See **Annexure 3** for extracts of relevant sections from all these laws. These legislative instruments offer targeted provisions for individuals with developmental disabilities and intellectual disabilities (ID); mental health conditions, and all 21 disabilities, respectively.

The NT Act was enacted in the late 1990s, (pre-dating UNCRPD) primarily in response to advocacy by parent groups of individuals with disabilities, particularly those with intellectual disabilities (ID). The motivation of this stakeholder group was to ensure guardianship of their children beyond their lifetimes. The Act established the National Trust to promote the welfare of its target population (i.e., persons with ASD, CP, MD, and ID). However, the subsequent developments, including the adoption of the UNCRPD by India, and the shift away from the medical model have revealed that the NT Act is anachronous.

MH Act and RPwD Act were enacted after India ratified the UNCRPD and these Acts are more aligned with the tenets of the UNCRPD.<sup>14</sup> **Table 1** provides an overview of the differences in the approach of the NT Act and the RPwD Act on legal capacity and legal guardianship.

The legal landscape extends beyond these specific enactments. Apart from the specific disability-related laws, there are other legislations (**See Annexure 3**), such as the Indian Contract Act of 187, which is based on an assumption that decision-making capacity is enmeshed with legal capacity.

Judicial precedents (**Box 4**) also play a significant role, with pronouncements by the Supreme Court and High Courts contributing to the understanding of capacity and decision-making. This reliance on both legislation and judicial pronouncements underscores the complexity of navigating the legal landscape in this area.<sup>15</sup>

<sup>14</sup>Dhanda, & Gombos. (n.d.). Consultation Paper drafted under the auspices of the National Trust. Retrieved February 7, 2024, from <https://disabilitystudiesnalsar.org/nt.php>

<sup>15</sup>Agarwal, & D’Souza. (2021, March). Decision Making for Persons with Impaired Capacity. In Vidhilegalpolicy.in. Retrieved July 31, 2023, from [https://vidhilegalpolicy.in/wp\\_of\\_taking\\_care\\_of\\_themselves/](https://vidhilegalpolicy.in/wp_of_taking_care_of_themselves/)

**The current legal framework in India governing capacity and decision-making employs outdated and problematic terminology. Terms such as "incompetence," "unsound mind," and "lunacy" are frequently used interchangeably across various laws, often with the consequence of denying individuals their legal personhood.**

For instance, the **Indian Contract Act, of 1872**,<sup>16</sup> limits the ability to enter into contracts to individuals of "sound mind," while the Bharatiya Nyaya Sanhita, 2023<sup>17</sup> (BNS) allows individuals deemed of "unsound mind" to escape criminal responsibility. Similarly, being categorized as a person of "unsound mind" often serves as a disqualification under various legal provisions.

**3.5. Decision-making capacity holds intrinsic value, independent of the outcomes of the decisions themselves**



**The quality of our choices, wise or unwise, does not negate our right to make them. Denying autonomy or decision-making capacity based on subjective evaluations of "good" choices contradicts core liberal principles.**

Legal scholar Ronald Dworkin's "integrity view" of autonomy offers a fresh perspective compared to traditional views focused solely on individual well-being. Dworkin argues that valuing autonomy hinges on respecting a person's inherent integrity, regardless of the outcome of their choices. He posits that autonomy empowers individuals to shape their lives based on a "coherent and distinctive sense

of self," encompassing their values, character, and convictions. Each decision contributes to their narrative and desired self-conception, deserving respect and recognition.<sup>18</sup>

Importantly, the integrity view disregards the consequences of choices. For instance, a health-conscious person who smokes exemplifies this. Their autonomy is acknowledged based on their ability to choose within their value system, preserving their integrity (**Figure 1**). Nevertheless, assessing decision-making capacity remains complex. It requires balancing individual autonomy with well-being while considering cultural, social, and economic factors. This complexity creates challenges when developing laws around decision-making, especially for individuals with disabilities. However, international charters, conventions, and laws (both International and Indian) have moved towards recognizing the legal capacity as a fundamental human right for persons with disabilities.



**Figure 1: Dworkin's Integrity View states that autonomy matters, regardless of the consequences of choices.**

<sup>16</sup>Section 11, Indian Contract Act, 1872.

<sup>17</sup>Section 22, Bharatiya Nyaya Sanhita, 2023

<sup>18</sup>Dworkin, R. (1986). Autonomy and the demented self. *The Milbank Quarterly*, 64(Supplement 2), 4-16, 8.

### 3.6. Different decisions demand different levels of cognitive and functional abilities



For example, in healthcare, the paramount value placed on individual autonomy necessitates broader participation in decision-making, even for individuals with higher levels of impairment. This stems from the fundamental principle of respecting patient self-determination. Notably, capacity is assessed on a decision-specific basis, tailored to each treatment option under consideration.<sup>19</sup> In contrast, financial and property decisions often necessitate more comprehensive capacity assessments, encompassing an individual's ability to manage their finances and make sound judgments that impact not only themselves but also potentially third parties who rely on the consistency of such decisions. Consequently, capacity in these situations is typically assessed on a larger basis, encompassing the individual's overall ability to handle financial matters rather than focusing on specific transactions.

Certain decisions, such as marriage, sexual relations, and participation in elections, pose unique ethical challenges from the perspective of the person with disabilities. Implementing substituted decision-making measures can effectively exclude individuals with impaired capacity from making these choices, potentially creating a conflict between protecting them from harm and respecting their fundamental rights.<sup>20</sup>

<sup>19</sup>Buchanan, A., & Brock, D. W. (1986). Deciding for others. *The Milbank Quarterly*, 64(Supplement 2), 17-94, 47.

<sup>20</sup>Agarwal, & D'Souza. (2021, March). Decision Making for Persons with Impaired Capacity. In Vidhilegalpolicy.in. Retrieved July 31, 2023, from <https://vidhilegalpolicy.in/wp-content/uploads/2021/03/Decision-Making-for-Persons-with-Impaired-Capacity-Full.pdf>

**Table 1: Comparison of the NT Act and RPwD Act on various aspects of legal capacity and legal guardianship**

Features	National Trust (NT), Act 1999	Right of Persons with Disability (RPwD) Act, 2016
Application	This Act applies to individuals with disabilities who are diagnosed with conditions related to ASD, CP, ID (previously known as mental retardation), or any combined occurrence of two or more of these conditions. Additionally, the Act encompasses individuals experiencing severe MD.	The Act applies to individuals with disabilities, defined as "persons experiencing long-term physical, mental, intellectual, or sensory impairments which, when interacting with various barriers, hinder their full and effective participation in society on an equal basis with others

Features	National Trust (NT), Act 1999	Right of Persons with Disability (RPwD) Act, 2016
<b>Objective</b>	<p>The Act's primary goal is to establish the National Trust, a national body dedicated to furthering the welfare of individuals with disabilities. This encompasses <b>comprehensive oversight of matters concerning guardianship and decision-making, alongside promoting their socio-economic well-being.</b></p>	<p>This Act serves as India's implementation of the UNCRPD. It aims to advance the rights of individuals with disabilities, including autonomy and equality, through various provisions. These include:</p> <ul style="list-style-type: none"> <li>• <b>Non-discrimination:</b> Prohibiting discrimination against individuals with disabilities in various spheres of life.</li> <li>• <b>Equal legal capacity:</b> Recognizing the equal legal capacity of individuals with disabilities, dismantling discriminatory practices that previously denied them agency in decision-making and participation.</li> <li>• <b>Access improvement measures:</b> Implementing measures to ensure accessibility and remove barriers that hinder their full participation in society.</li> </ul>
<b>Decision-Making Capacity</b>	<p>While the Act itself does not explicitly define "decision-making capacity" for individuals with disabilities, it does offer guidance through the process of appointing a guardian. The Local Level Committee, responsible for such appointments, must consider whether the individual with a disability genuinely requires a guardian to assist with decision-making. This implies an implicit understanding of decision-making capacity as the ability to make informed choices and manage one's affairs without undue influence.<sup>21</sup></p>	<p>Aligning with the UNCRPD principles, the Act acknowledges the equal legal capacity of all individuals with disabilities.<sup>22</sup> Consequently, it discards the concept of "decision-making capacity" as a basis for disenfranchisement. However, recognizing that some individuals may require support in exercising their legal rights, the Act introduces the concept of a <b>limited guardian</b>.<sup>23</sup> This mechanism allows for support in making specific legal decisions when the individual's capacity is deemed insufficient.</p>
<b>Process of appointment of Guardian</b>	<p>The Act draws on the traditional guardianship model but takes the consent of the PwDs for the appointment of a guardian. This guardian assumes responsibility for the person's care, maintenance, and property.<sup>24</sup> While the Act avoids directly referencing decision-making, it implies the guardian acts as a surrogate decision-maker once appointed. However, crucially, the Act lacks clear principles or standards guiding the guardian's actions, raising concerns about the potential for undue influence and compromised autonomy.</p>	<p>While the Act doesn't explicitly outline a formally supported decision-making approach like the UNCRPD, it echoes its principles through the emphasis on <b>supporting individuals with disabilities in exercising their legal capacity</b>.<sup>25</sup> This support is implicit in various provisions. Additionally, the Act recognizes that even with support, some individuals might still struggle to make specific legal decisions. In such cases, upon application to the District Court, a <b>limited guardian</b> can be appointed to assist with those specific decisions, ensuring legal capacity is upheld while acknowledging individual needs.</p>

<sup>21</sup>Section 14(3)(a), National Trust Act, 1999.

<sup>22</sup>Section 13, Rights of Persons with Disabilities Act, 2016.

<sup>23</sup>Section 14, Rights of Persons with Disabilities Act, 2016.

<sup>24</sup>Section 15, National Trust Act, 1999.

<sup>25</sup>Section 14, Rights of Persons with Disabilities Act, 2016.

Features	National Trust (NT), Act 1999	Right of Persons with Disability (RPwD) Act, 2016
<b>Safeguards and Limitations</b>	The Act establishes safeguards for individuals under guardianship by mandating appointed guardians to disclose details of the person's property after appointment and submit annual reports. These measures promote transparency and accountability. Furthermore, guardianship can be revoked if the guardian abuses, neglects the person, or misuses their property, ensuring the person's well-being and protecting their rights. <sup>26</sup> However, the complaint can be only made by parents, relatives or next-friends, not by the PwDs themselves.	The Act acknowledges the importance of supported decision-making and introduces safeguards to prevent abuse and conflicts of interest. It prohibits support persons from assisting where conflicts arise, protects the validity of past transactions even if the support person changes, and forbids undue influence. However, the crucial aspects of detailed procedures and clear guidelines for addressing actual abuse or conflict situations are absent. This lack of clarity could leave individuals vulnerable in such situations. <sup>27</sup>

#### Box 4: Judicial Pronouncement on Decision-Making and Legal Capacity

- **Suchitra Srivastava v. Chandigarh Administration**<sup>28</sup> is one of the earliest legal precedents that recognized the decision-making capacity of persons with Intellectual Disabilities (ID). The Court emphasized respecting the decisions of those with mild to moderate disabilities while distinguishing them from severe cases requiring supervision. It held that restricting freedom of choice violates privacy, autonomy, and dignity under Article 21 of the Constitution.
- **R. Parthiban v. State of Tamil Nadu**<sup>29</sup> highlighted the ongoing struggle of persons with ID to assert their decision-making capacity, despite universal legal capacity being rooted in the Indian Constitution. The Court criticized outdated legal terminology and referred to the UNCRPD to contextualize rights for persons with disabilities in India. **R. Parthiban v. State of Tamil Nadu**<sup>30</sup> also interpreted Article 12(4) of the UNCRPD to recognize persons with mental and intellectual disabilities possess legal capacity as “persons” under the law.
- **Ravinder Kumar Dhariwal v. Union of India (2021)** emphasized that universal legal capacity augments the need for supported decision-making of persons with disabilities. The Supreme Court observed that substituted decision-making undermines agency and violates universal legal capacity. It held that denying legal capacity outright breaches rights under Article 21 of the Constitution.

<sup>26</sup>Section 17, National Trust Act, 1999.

<sup>27</sup>Section 13(4) & (5), Rights of Persons with Disabilities Act, 2016

<sup>28</sup>(2009) SCC 1

<sup>29</sup>(2009) WLR 1065

<sup>30</sup>(2009) WLR 1065

- **Navtej Singh Johar v. Union of India.**<sup>31</sup> recognized individual dignity and decisional autonomy as integral to the fundamental right to privacy and a violation of Article 21. The Court emphasized that the rights of a discrete and insular minority are as sacred as those of other citizens. The Court also noted that the right to autonomy is one of the four cardinal principles on which our constitution is based. Universal legal capacity for persons with ID can, therefore, be interpreted as a fundamental right under the Constitution.
- The case of **Vikash Kumar v. Union Public Services Commission**,<sup>32</sup> recognized reasonable accommodation for persons with disabilities as a right, stating that not providing the same is tantamount to discrimination. This case affirmed the legal capacity of a person with a disability and its deprivation as a violation of the fundamental right to equality.

**Despite jurisprudence and laws to the contrary, persons with ID (even those who have high cognition) face de facto barriers to their legal capacity through denial of reasonable accommodations.**

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<sup>31</sup>(2018) 10 SCC 1  
<sup>32</sup> (2021) 5 SCC 370





**Part 4**

**Challenges Faced by  
Persons with Disabilities  
In India Relating to  
Legal Capacity & Legal  
Guardianship**

**4. Challenges Faced by Persons with Disabilities In India Relating to Legal Capacity & Legal Guardianship**



In India, the National Trust (NT) Act, 1999, enacted in the late 1990s, primarily focused on legal guardianship for persons with developmental and intellectual disabilities (including CP, ASD, ID, and MD) to provide for their well-being and maintenance, as well as managing property and finances. Later, human rights frameworks such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2007, emphasized **individual autonomy and supported decision-making (recognizing the individuals' legal capacity while scaffolding their decision-making capacity- See Box 3)**. India's subsequent ratification of the UNCRPD led to the enactment of the Rights of Persons with Disabilities Act (RPWD) in 2016. **The RPWD Act aligns with the UNCRPD, promoting supported decision-making and prioritizing individual autonomy, but NT Act, which advocates substituted guardianship, has not yet been repealed. This leads to a persistent discrepancy - See Figure 2.**

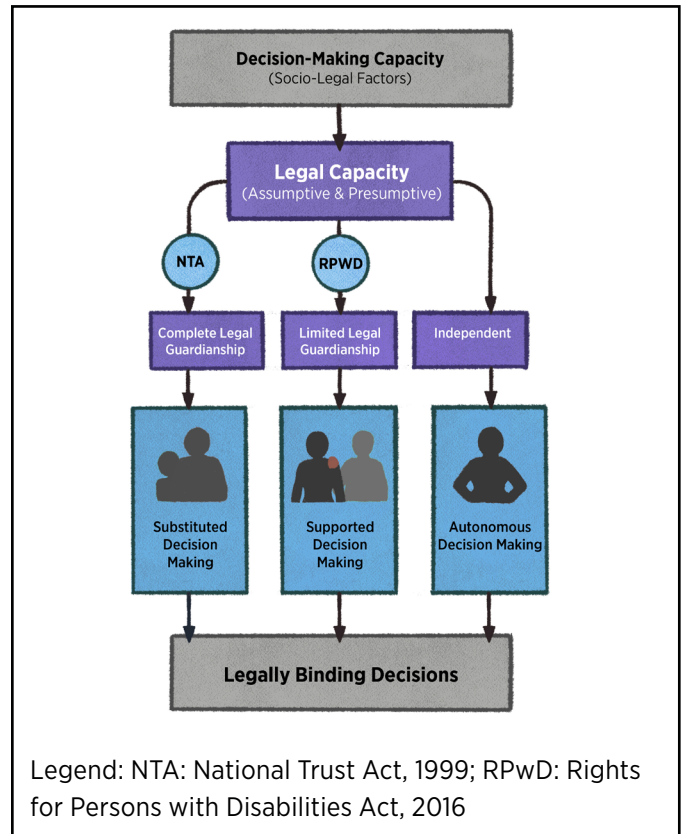


Figure 2: The Relationship between Legal Capacity, Decision-Making Capacity, and Legal Guardianship Based on the Literature within the Indian Context

**Figure 2** represents the relationships between decision-making capacity, legal capacity, and legal guardianship in the context of Indian laws. Legal capacity grants recognition and rights under the law, operationalized through the individual's ability to understand contexts/ situations and make decisions. For persons with disabilities, decision-making capacity can be reduced and/or perceived as reduced by the persons and systems (socio-legal factors such as lack of awareness) that they interact with. If decision-making capacity is not reduced, it is likely that the person with disability can enter into legally binding decisions independently. In cases where decision-making capacity is reduced, legal guardians are appointed under law to act on their behalf.

In India, two laws govern legal guardianship for persons with intellectual and developmental disabilities: the National Trust (NT) Act, 1999 and the Rights for Persons with Disabilities (RPwD) Act, 2016. However, The two acts define the role of a guardian differently. The NT Act provides for substituted decision-making, thereby replacing the legal capacity of the person with disabilities. The RPwD Act calls for supported decision-making, whereby the guardian is expected to act in consultation with the person with disability. These differing expectations can create conflict in practice and pose implementation challenges.

The international position seems to be well settled – where there is lower capacity, the person with disability can still make decisions with support and must be given the same. Despite progress in laws and charters, individuals with significant intellectual, cognitive, and psychosocial disabilities in India continue to grapple with substantial or even complete limitations in their decision-making autonomy. They frequently encounter assumptions that they lack the capacity to navigate their own lives, often being perceived as individuals requiring protection. Moreover, many of these individuals face physical isolation and social and economic exclusion, leaving them without meaningful choices or the opportunity to shape their life trajectories, exercise independent decision-making and ultimately, depriving them of their legal capacity.<sup>33</sup>

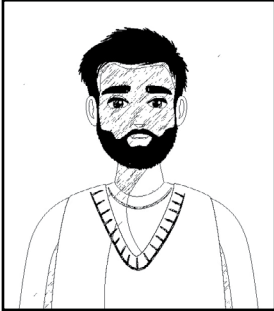
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<sup>33</sup>Bach, M., & Kerzner, L. (2010) A New Paradigm for Protecting Autonomy and the Right to Legal Capacity, Prepared for the Law Commission of Ontario. Retrieved January 2024, from <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>

## 4.1. Illustrative Case Studies



## Sunil's Journey: Dilemma in Exercising Independence based on Decision-Making Capacity



Name: Sunil

Age: 39

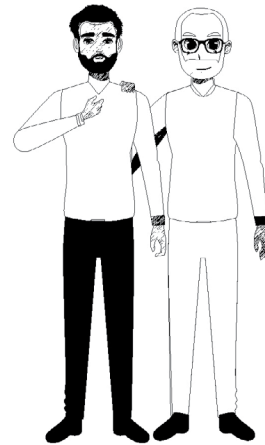
Home: Pune

Work: Part-time at a canteen (manning the tea and coffee stations)

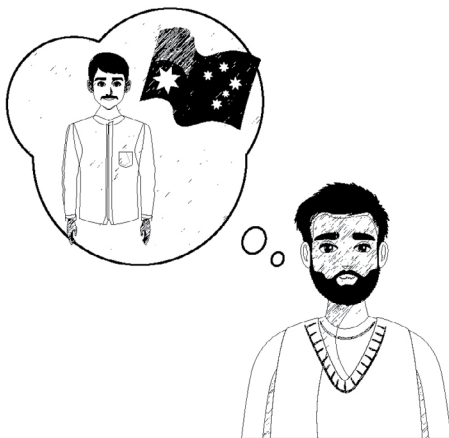
Interests: Watching TV, cooking, going out



Sunil is diagnosed with severe intellectual disability. Sunil requires constant support to make basic choices, such as what to eat or wear.



Sunil is aware of his earnings but doesn't understand the value of money; his father manages his finances.

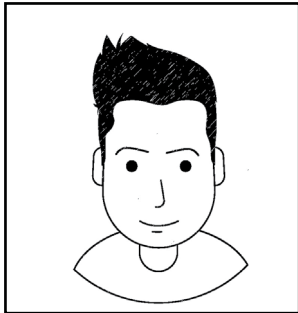


Sunil has an elder brother who is an Australian citizen but cannot be his legal guardian under the NT Act.



His father has created a trust to manage Sunil's finances and has planned for his future by establishing a group home where Sunil will live after his parents' time.

### Karthik's Journey: Dilemma in Living Autonomously in the face of Interaction between Self-Limitations and Society



Name: Karthik

Age: 22

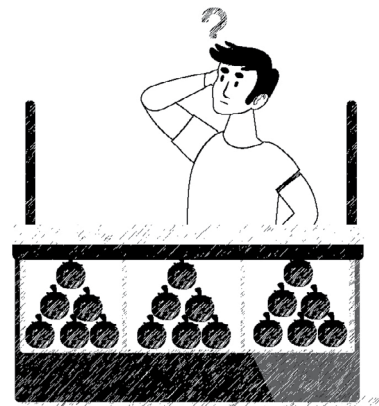
Home: Mumbai

Work: Visual artist, classical singer, and online doodling teacher

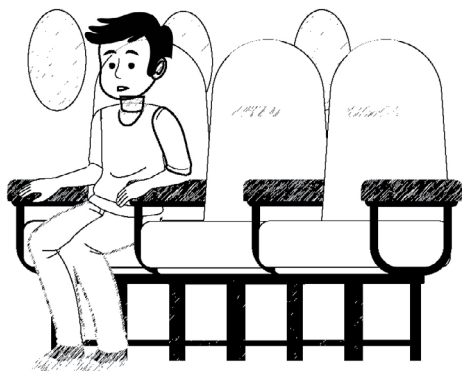
Interests: Art, singing, teaching



Karthik struggles with making major decisions and living independently, despite handling some day-to-day choices.



At a market, Karthik was overcharged (500 INR for six apples) due to his inability to recognize being exploited.



On a solo flight, Karthik experienced a panic attack, with no assistance from co-passengers.

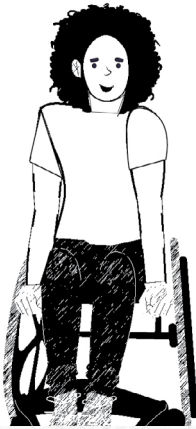


His parents set up a trust and group home for his future, while Karthik wishes to live alone, but his parents remain concerned.

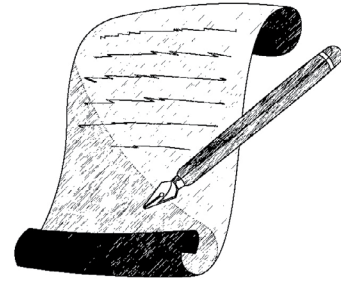
## Shruti's Journey: Dilemma in Navigating Institutional Barriers to Claim Autonomy



Name: Shruti  
Age: 28  
Home: Raipur  
Education: Pursuing graduation



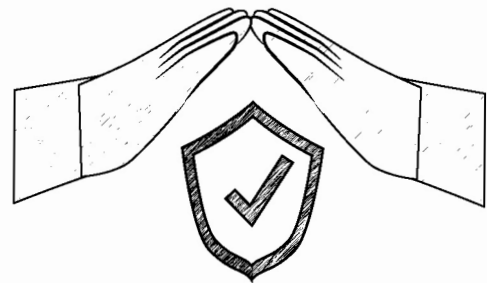
Shruti excels academically and is fiercely independent. Despite living with Cerebral Palsy, her parents fully support her wish to live independently and make her own decisions.



Shruti's difficulty in communicating and signing documents prevents her from opening bank accounts or accessing loans, even though she is legally capable.



Service providers like banks and insurance companies fail to provide the necessary support, denying her the ability to exercise her rights.



Shruti was compelled to appoint a legal guardian, undermining her independence and legal capacity.

To illustrate the challenges faced by persons with disabilities further, the cases of Sunil, Karthik, and Shruti demonstrate how the outer world can be a non-conductive territory for persons with disabilities. Sunil's reliance on help for navigating simple tasks like crossing the road reveals the inherent inaccessibility of public infrastructure that can restrict independence. Karthik's experience on the flight, highlighting societal intolerance towards meltdowns, exemplifies the social barriers that can isolate and marginalize persons with disabilities. Shruti's struggle to open a bank account, despite possessing legal capacity, underscores the pervasive issue of societal prejudice and a lack of understanding surrounding disability. Financial institutions fail to acknowledge the legal capacity of persons with disabilities and do not provide reasonable accommodations to facilitate the exercise of their legal capacity. Shruti is thus denied the right to manage her finances based on unfounded assumptions about her legal capacity. RR said, "If you look different, you are treated differently," encapsulating the unfortunate reality that physical or cognitive differences can lead to discrimination and unequal treatment.



**Part 5**

**Research Findings**





5. Research Findings

**Finding 1 : On Social Influencers of Legal and Decision-Making Capacity**

Inner and outer circles of a person with disability shape their legal capacity and autonomy. There is an intricate relationship between parental-cultural attitudes, as well as socio-institutional structures, and the way they affect the legal capacity of persons with disabilities and, thus, their autonomy.

**An enabling environment needs to be created for children to learn to make decisions**

-Dr. SP (Director, Consultant Psychiatrist)

We found that decision-making and legal capacity are closely linked to the environment in which a person with disability lives (Figure 3). Parents and/or guardians form the closest network for persons with disabilities, and their inner circle continues to influence their lives across all ages. Institutional and social factors are encountered as the person with disability grows older, often conflicting with the legal landscape in India. This conflict is further complicated by a lack of awareness on the terms of “legal capacity” and “legal guardianship”.

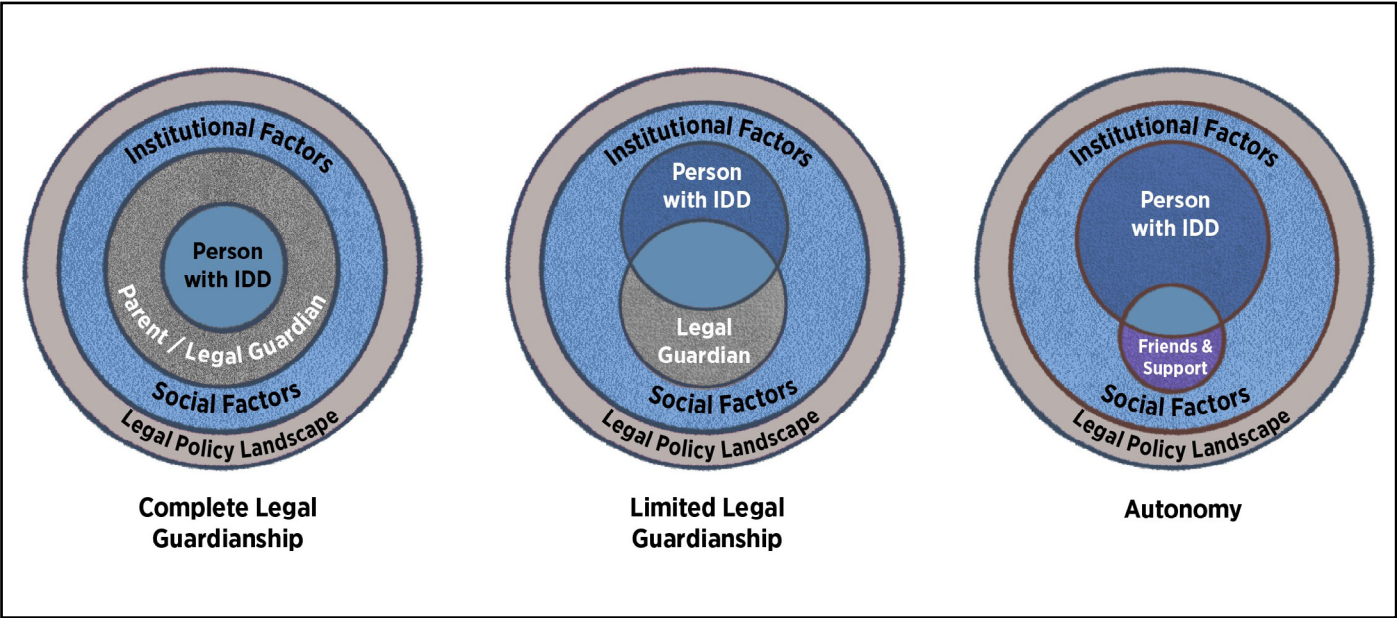


Figure 3: Interaction of Factors in Determining Autonomy and Agency for Persons with Disabilities

### Persons with Disabilities and their Immediate Family (Inner Circle)

The term "inner circle" encompasses the immediate family. **People with CP in the sample, who are now living independently, revealed that they were brought up in an environment that encouraged decision-making and independence from a young age.** Those with CP and with no cognitive impairment (i.e., RR, SP, and Dr. AL) in our sample are independent and have made all life decisions for themselves. RR, now a strong advocate for CP rights, expressed that he was raised in a supportive home that encouraged him to make his own decisions and live independently. Additionally, SP, currently a law student, shared that she was raised in a supportive environment with a "normal" upbringing.

**At home, I had a very basic and a very normal upbringing. Nobody has treated me as if I belong to a... as if I am from a special category ...**

**-SP, 26 ( A person with CP)**

Parents play a pivotal role in shaping their child with disabilities' abilities and decision-making capacity. Participants in FGD 1 with persons with disabilities highlighted the support and environment their parents provide to make day-to-day decisions and encourage financial independence. According to persons with disabilities, their parents are their greatest enablers. However, due to outer circle factors, parents sometimes restrict autonomy by making larger decisions on behalf of their child. For

example, as in the case of SrP, 30 years old with CP and mild-moderate intellectual disability, her mother, Dr. AR, expressed fear of letting her daughter make financial decisions or handle daily transactions because of SrP's low numeracy skills. Dr. AR explained that the world lacks the patience to allow SrP the time she needs to do the math, which increases the chance of her being cheated by outsiders.

**While parents generally provide opportunities for their child to make decisions, they remain cautious about the extent to which these decisions are exercised, taking societal attitudes and norms into account.**

### Social/Institutional/Law-Policy (Outer/ External Circle)

The term "outer circle" encompasses the societal structures, institutions, and physical infrastructure that shape our world. This circle comprises factions (actors and factors) who are beyond the familial inner circles. While parents are naturally protective of all children, this protectiveness can intensify when it comes to persons with disabilities, driven by a deep-seated fear of societal discrimination and the harsh realities of the "outer circle." Several parents or guardians shared stories where their own experiences with the institutions such as special/mainstream schools, negativity fueled banks and increased protectiveness even for their adult children.

Experience and struggle of SP, a person with CP in her everyday life:



I am individually a person with multiple disabilities, low vision, as well as spondylitis with cerebral palsy, and growing up here in a small city like Bhubaneswar where people are not as aware people often equate a person with a physical disability with a mental disability. So, you have to fight for everything from pillar to post - starting from going mainstream for your education till going to a public place

-SP, 26 ( A person with CP)



The FGD 1 with persons with disabilities revealed their stark experiences with society, showcasing both the challenges and potential for support.

"Bus conductors often refuse to help me, leaving me no choice but to spend extra money on private transport."

"One time, I accidentally boarded the wrong bus, and it caused so much panic for my parents."

"Thanks to the efforts of our local NGO, we've seen traffic police step in and actually help us. It shows that change is possible."



Figure 4: Inaccessible Public Transportation For Persons with Disabilities

**(Figure 4)** Highlights the persistent issue of inaccessible public transportation for persons with disabilities, which can influence perceptions of their decision-making and legal capacity. In one case, despite seeking help from the police, they faced harassment and blame for leaving their son alone. This incident exemplifies the societal bias that persons with disabilities lack decision-making capacity, leading to diminished confidence in their ability to make decisions and their parents' reluctance to allow them to live independently.

All members of this group work in the same workplace located in a bustling area and face daily challenges crossing heavy traffic. Through advocacy and awareness efforts, they have built a strong relationship with the local traffic police, who now assist them in crossing safely. The FGD reveals the duality of experiences faced by persons with disabilities in public spaces: persistent barriers and discrimination, but also instances of positive collaboration and support.

**The inner and outer circles of an individual's life intertwine to weave a tapestry, exerting both direct and indirect influences on the decision-making and legal capacity of persons with disabilities. Even though the inner circles (i.e., the parents) often have the best intentions, providing space and fostering decision-making skills, the fear of the outer circle can paradoxically push them towards excessive protection, particularly when decisions involve outer circle factors. This creates a tug-of-war — a constant struggle to balance the need to safeguard persons with disabilities from harm with the equally crucial need to nurture their autonomy and self-determination. This highlights the cyclical nature of the problem: societal bias against persons with disabilities shapes the inner circle's behavior, which, in turn, can hinder the development of independence within persons with disabilities, potentially perpetuating the cycle.**

## Finding 2 : On Legal Capacity

Most parents, despite being well-educated and aware of multiple aspects of disabilities, did not fully understand the term 'legal capacity' and were unaware of the rights of their adult child. The same is true for those with disabilities. Unless there are conscious efforts to raise awareness and build capacity—whether a parent or a person with a disability themselves—a majority will remain marginalized.

All parents and guardians we interviewed were well-educated, from a higher socio-economic status, and closely connected to their child with disabilities' lives. Despite the advantages, almost all parents and guardians of persons with disabilities lacked an understanding of the term "legal capacity". This was reflected in their inability to articulate what the term meant, as well as in their understanding and knowledge of their child's rights as an adult person with a disability. Consequently, parents fail to recognize their adult child as autonomous under the law.



**Legal rights for people with disabilities - I wouldn't say that I'm fully aware. But I try to read up. I try to know as much as I come across, but there could be a lot that I may have missed.**

-SD, a parent to a 21-year-old with ASD and a trained special educator



Even a parent turned disability rights advocate is unaware of the accommodations that will be given to a person with a disability.



**Even the persons with the most severe disabilities should also have legal rights. Because at the end of the day, the law treats him [the same] if he does anything wrong, the law will not give him any concessions on it.**

-SB a parent of a 39-year-old with ID, AB, and a member and ex-president of Parivaar - Parents' movement for the welfare and protection of rights of Persons with 'Intellectual and Developmental Disabilities' (the largest, oldest, and most active parent network for persons with disabilities in the country)<sup>34</sup>



When persons with disabilities were asked about “legal capacity” and their rights during individual interviews, RR, Dr. AL, and SP ( people with CP and disability advocates), knew about legal capacity. Persons with disabilities in FGD 1 (whose intellectual impairment levels were between moderate to severe) were aware of their “legal capacity” and rights because the NGO they are associated with raised their awareness. The NGO achieved this by reading out and providing training on the RPwD Act.

<sup>34</sup> <https://www.parivaarncpo.org/pages?id=36>

### Finding 3 : On Decision-Making Capacity

Parents understand the term “decision-making” in general and in the context of their children with disabilities, but do not allow room for decisions that may have negative consequences.

Parents and guardians of those with ASD and ID are aware of the concept of decision-making and how it applies to the person with disabilities. However, this remains confined to allowing their children the autonomy to make smaller everyday decisions, such as what they want to wear, eat, or where they want to go. Sometimes, autonomy in decision-making is extended to choices regarding work and education (for those with higher intellectual capacity). However, most of the parents we spoke to still hold control over their child’s decisions.

**For most young adults, the years between 18 and 25 mark a pivotal transition towards independence. This period is characterized by establishing one’s own identity, navigating personal and professional choices, and charting a course for the future. The reluctance of parents to let go and permit the adult children with disabilities to make decisions stems from a complex web of factors, including deeply rooted anxieties about their child’s well-being due to cognitive or physical limitations, fear of societal discrimination, and a lack of understanding about legal capacity and the role of a legal guardian. the cycle.**

One reason for parents to hold control over their adult children with disability is (half of the parents from the individual interviews in our sample expressed) that decision-making autonomy is synonymous with being responsible for the consequences of the decision. Parents emphasized the need for preparedness to face these consequences (i.e., the larger the consequence the more consciously the decision needs to be made). They indicated that decisions are made within a framework or boundaries set within a social context.



**When you are an adult, whatever decision you're taking, you are responsible for that -. If an unfortunate consequence comes you have to face that.**

- CG, a parent and legal guardian to a mother with a 28-year-old with Down's Syndrome



**To me, decision-making is a responsibility..., the awareness and alertness of deciding anything goes up with the seriousness of the issue about which we are making that decision. Like - it's easy to make wrong decisions about something trivial, so to say, but it's more intricate in issues that are of more importance in our lives. So, decision-making is a responsibility that gives us the desired results that we are planning or that we are expecting out of our decisions.**

-SD, a parent to a 21-year-old with ASD and a trained special educator



Another reason for parents to retain control over their children's decisions is that, having been closely involved in the upbringing of their child with a disability, they understand their child, relate to their struggles with society (see Finding 1 - Inner and Outer Circle Influence), and thus tend to be more protective. Their approach to autonomy and legal capacity is informed based on their child's decision-making abilities or, at the very least, their understanding of them. For those with higher intellectual disabilities, parents believe that even for everyday, not-so-consequential decisions, their actions are more automatic or less thought-out rather than conscious decisions.<sup>35</sup>

<sup>35</sup>[A distinction needs to be made here – actions for persons with ID and developmental disabilities are based on automatic/less thought-out decisions or decisions through repeated training (as illustrated in the case of Sunil). Further research needs to be done to understand the consciousness of decisions for this group - to distinguish between socio-cultural (inner and outer circle) influences and the influence of the disability.]

He will say okay and he'll only pull out (clothes) randomly, whatever is kept. It is not conscious

-VY, a parent from Bengaluru of 18-year-old son with ASD

**Most parents determine and limit their child's decision-making capacity based on their lived experiences while raising them. According to interviews and parent narratives, people with disabilities make smaller everyday decisions, while larger decisions regarding finances and property are made by the parents, particularly in cases of ID and ASD, regardless of the level of functioning.**

Most people with ASD and ID (with moderate to severe decision-making impairment) were found to make more everyday decisions relating to their choice of food, clothing, outings, and the kind of work they would like to do. Larger decisions regarding finances were made by the parents, who expressed that their child did not have numeracy skills and did not understand money valuation. In fact, all parents interviewed indicated that their child had no concept of money and did not understand its value.

...we, wherever possible, encourage him to make a mistake and then learn from his mistakes., because of his IQ [being] very low, he doesn't have time sensitivity, he doesn't have money sense at all so he is not taking any such decision. But we have again brought him to a level where he knows that he should not decide and that he comes back to us.

- SB, a parent to a 39-year-old with ID, AB

While interviewing AB, researchers found that AB too had imbibed this conditioning. He expressed repeatedly that the more consequential decisions required adult supervision. For example, going out with friends or buying fruits from the market cannot be done without an adult accompanying him.

From conversations with people with ID and ASD (those with moderate cognitive abilities), we found that they are capable of understanding larger, more consequential decisions regarding their life, such as finances, property, choice of partners, and living independently. However, they expressed that their parents provided only limited opportunities to exercise their legal capacity and autonomy as expressed by them.

**In most cases, individuals with disabilities face a stark contrast – day-to-day autonomy is limited as major decisions are reserved for parents or guardians**

-Dr. SP (Director, Consultant)

**Parents provide a nurturing and caring environment for their children. They enable the best for their children; however, they do not consciously foster larger life skills such as financial independence in their children. One reason for this is because all their efforts are spent trying to provide their children with the basic education and life skills required for daily living in a non-supportive system.**

#### Finding 4 : On Legal Guardianship

There are variations in the practice of legal guardianship due to differing knowledge of decision-making capacity and legal capacity among parents, the community, and institutions regarding persons with disabilities.

Despite the enactment of the RPwD Act, which provides the process for (limited) legal guardianship that is more beneficial for persons with disabilities, the mechanism for appointing legal guardians under the older NT Act, 1999, remains highly prevalent.<sup>36</sup>

#### Awareness about legal guardianship is often murky

The interviews with parents and the FGDs revealed a trend: even after reaching 18 years of age, parents of persons with disabilities did not relinquish control. Some parents believed they could remain guardians (continuing their status as natural guardians) even after their child turned 18, oblivious of the legal limitations—namely, that a parent cannot act explicitly on behalf of the adult person with disabilities without their consent. The practice by banks, which allows parents to hold joint accounts with their adult child with a disability and operate the bank account on their behalf, further shrouds the deprivation of legal capacity and highlights poor awareness of the need for a formal legal guardianship certificate.

<sup>36</sup> This may be because parents who have taken up guardianship in our study, have older children who turned 18 before the enactment of the RPwD Act, 2016



VY, a father of an 18-year-old boy with ASD, acknowledged having a vague idea and promised to pursue it "when required."

Furthermore, parents expressed little knowledge about the specific provisions of limited guardianship under the RPwD Act.



See awareness is very poor, at the village level especially about legal guardianship certificates. We [the NGO] keep telling the parents (those who are government employees), the people who have property, to get the Legal Guardianship certificate. But, many of them think that a will is enough.. Some of the parents don't understand. In the case of poor people - they don't have any property, and they are not much bothered about legal guardianship certificates...

-AH, an NGO Founder and a Local Level Committee (LLC) member at Hasan, Hospet, Karnataka



You mentioned the limited guardianship... yeah... I do not know much about that.

-SD,21 (A person with ASD)



During the FGDs with persons with disabilities, participants expressed their apprehension and a lack of knowledge regarding limited guardianship. Some participants stated that being informed about the advantages and disadvantages of guardianship under these two legislations would help them make better decisions. This lack of clarity could be one of the reasons why guardians or persons with disabilities do not opt for limited guardianship under the RPwD Act.



While RPwD aims to substitute the NT Act in terms of legal guardianship and introduce the concept of supported decision-making, the RPwD Act fails to adequately explain this new system.

-SCV, a disability rights lawyer.



**Parents take up legal guardianship across the wide range of decision-making capacity impairment of the person with disabilities.**

The study found that there are large variations in how legal guardianship is approached among parents of those with ID, ASD, and CP. One of the major influencing factors is the cognitive levels (real/perceived by the parents) of their child. **Figure 5** below maps out how legal guardianship is taken up based on the level of decision-making impairment<sup>37</sup> and the physical impairments of persons with disabilities.

Capacity	No Decision-Making Capacity Impairment	Mild Decision-Making Capacity Impairment	Moderate Decision-Making Capacity Impairment	Severe Decision-Making Capacity Impairment
No Physical Impairment	✗	☑ ✗	☑ ✗	☑ ✗
Mild Physical Impairment	✗	☑ ✗	☑ ✗	☑ ✗
Moderate Physical Impairment	✗	☑ ✗	☑ ✗	☑
Severe Physical Impairment	✗	?	?	?

**Legend:**

- ☑ - Legal Guardianship taken up by parents
- ✗ - Legal Guardianship not taken up
- ☑ ✗ - Variations in legal guardianship status of parents (some taken up vs. others having not taken up)
- ? - Unsure of how legal guardianship plays out for these groups (need for representations)

Figure 5: Legal Guardianship based on decision-making and physical impairments.

**Figure 5** matrix shows that for those with no decision-making impairments but varying degrees of physical impairment (particularly in the case of RR, SP, and Dr. AL who are persons with CP), live autonomously. Whereas, for those with mild/moderate/severe decision-making impairments, particularly those with ID and ASD, it was observed that parents have either assumed guardianship or are considering it, especially for those aged 18–30 years.

<sup>37</sup>Note: Decision making impairment was based on the researchers understanding of capacity after interactions with persons with developmental disabilities and from parental narratives. We also noted that IQ and decision-making capacity were not related. However, these are not objective findings. Further research needs to be done to establish this relationship in India.



### Finding 5 : Challenges Associated With the Process of Legal Guardianship

#### Lack of law-friendly family support for legal guardianship options.

Rule 17 of the NT Act explicitly mandates that only Indian citizens and residents<sup>38</sup> can be legal guardians. In the study, parents cited that they have only one child who has a disability, or another child who resides abroad, or relatives who lack the proximity and capacity to assume guardianship.

Two parents revealed that their other adult children, who have families of their own and resided abroad, could not be considered for guardianship due to their foreign citizenship and lack of domiciliary presence—a limitation recognized in the NT Act.<sup>39</sup>

However, the mother of a 33-year-old son strongly opposed the rule that a foreign national sibling cannot be considered for legal guardianship under the Act.<sup>40</sup>

<sup>38</sup>Rule 17(1)(iii)(a) of National Trust Rules 2000

<sup>39</sup>The NT Act assumes that the legal guardian is responsible for the person's maintenance, wellbeing, and care of property on behalf of the person with disability. In such a case, by default the guardian has to remain or live in close proximity to fulfill their obligations. Therefore, a person who does not reside with the person cannot assume the role of a legal guardian as per the NT Act.

<sup>40</sup>[It may be noted that in the case of SuB and her son physical care has been entrusted to the group home where they now reside. She argues from the perspective of financial and property-related guardianship)

<sup>41</sup>Regulation 12(6) of National Trust Regulations 2001



They [the siblings] have the moral responsibility, apart from [parents]. So if they are barred from making them a legal guardian, we have to find somebody else, that's a challenge for us. But the first [choice to entrust this] responsibility will be only with the siblings, No? But we can't expect every sibling to be in India nowadays, so we are trying our best, but I don't know how.... As a special citizen's family, we all have to fight...

-SuB, a mother of a 33-year-old son



The changing family structures create a lot of stress on parents and the only options left are long-term housing (described below).impairment and the physical impairments of persons with disabilities.

TG ( a person with ID) highlighted that the selection and appointment of the legal guardian are not straightforward considering that

- The domicile of the guardian should be the same as the person with disabilities.<sup>41</sup>
- Their age should not be greater than 10 years of the person with disabilities.

Parents have to think hard and find various options for ensuring that their child is taken care of.



Another important factor is that the Guardian should be at least at the age of children plus five or minus five, then only there will be a long period to sustain these children. Otherwise, if they are of equal age [as the parents], there is no point, the guardian himself dies, then who will be the next guardian? That also we have thought [about]. One advocate told us that we are opening a trust account also - an individual beneficiary Trust in which our close relatives or friends can add them as a trustee for this boy and these trustees will supply the legal guardian. Once we are dead, this trustee, one of the trustees will be made a legal guardian and we will also be a member of the society so that from all angles he will be safeguarded. That is our idea. But again, who will apply to the National Trust? Trustees should be well informed and whether they are in a position to come to the state and stay. Everybody is, except the parents, others may not have that much interest or affinity or love and affection towards the boy, no? That will be a constraint. Anyway, something should be done



### Variance in State Wise Rules under RPwD Act - Several States Have not Notified Rules for Implementing the RPwD Act

The decentralized nature of limited guardianship under the RPwD Act means that the implementation of the provisions of the RPwD Act is reliant on each state notifying associated rules for the implementation. Several states have not yet notified the designated authorities responsible for implementing the provisions. A total of 24 states and union territories have implemented Limited Guardianship in some form, with either designated authorities, procedures, or both. Examples include Telangana, Chhattisgarh, Gujarat, Odisha, Punjab, and Tamil Nadu. 11 states and union territories have not designated authorities, procedures, or enforceable rules. These include West Bengal, Manipur, Uttarakhand, Lakshadweep, Ladakh, and others. Details of the pattern of state-wise enforcement of the RPwD rules are enlisted in **Annexure 4**.

### Guardian Under RPwD Act is For a Short Period Only

Some parents in the study have expressed that they are not comfortable applying for limited guardianship under the RPwD Act. TG expressed his concerns that although the NT Act has its jurisdictional problems, still limited guardianship is not better because it is for a very short period.



Limited guardianship means only for a specific period, say one year or one-and-a-half years. That is given by the commissioner of disability in each state. At the district level, a district disability officer entrusts the guardianship but that is for a very short period. One year only. Then you have to renew it or drop it. That is the condition of limited guardianship in RPwD. Permanent disability means it is difficult to get to the normal stage. Lifelong they have to suffer. What is the use?

-TG, parent to a person with ID



### Lack of Robust Follow-Up Mechanisms Under NT Act

While legal guardianship is crucial for managing finances and property, particularly in cases of pensions and inheritance, it can also become a tool for exploitation. The lack of robust follow-up mechanisms under the NT Act leaves persons with disabilities vulnerable to neglect or even financial abuse by their guardians after the lifetimes of their biological parents. This is especially concerning in cases where guardianship falls to siblings or other family members, where conflicts of interest and potential for unfairness can arise, such as misappropriation of funds or property, or neglect or abuse of the person with disability by the legal guardian. Additionally, the RPwD Act, which is otherwise a well-comprehensive piece of legislation, provides no details on support person roles or appointment processes. This raises concerns about safeguarding autonomy and preventing abuse.

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The problem is compounded by fragmented state rules. Some states designate District Judges as adjudicating authorities for appointing support persons, while others assign the role to State Commissioners for Persons with Disabilities (SCPD). This inconsistency leads to confusion, uneven safeguards, and potential delays or inefficiencies. For good practices, refer to **Box 5**.

#### **Box 5: Example of good practice to protect the person with disabilities under the NT Act**

Recognizing the vulnerability of persons with disabilities to abuse by family members (who have taken up legal guardianship after the parents), AH, LLC member founder of an NGO in Hospet, Karnataka, has taken proactive measures. The organization, led by a concerned member, conducts regular quarterly visits to persons with disabilities in the district to monitor their situation and ensure their safety.

#### **Difficulty in Transferring Legal Guardianship**

Transferring guardianship certificates from one jurisdiction to another often involves lengthy and cumbersome procedures, where the legal guardian feels overwhelmed. PD shared her experience while transferring her guardianship of her brother from her father to her and her husband's name. It was a long tedious and confusing process. (**Box 6**).

#### **Box 6: Story of Challenges in Transferring Guardianship**

PD's father took legal guardianship of PD's brother when he turned 18 in Nagpur, Maharashtra. However, a few decades later, as his health declined due to age-related ailments, PD's father sought to transfer the responsibility to PD and her husband. Having relocated to Hyderabad, PD assumed the process would be relatively simple. However, the Local Level Committee (LLC) presented a roadblock: they demanded a No Objection Certificate (NOC) from the Nagpur court before considering their application in Hyderabad. This unexpected requirement threw a wrench in their plans, causing significant inconvenience and delays. PD highlighted the unforeseen complexities associated with transferring guardianship across jurisdictions. The cumbersome procedures, coupled with a lack of clarity and communication, can be incredibly daunting for families navigating an already barrier-ridden landscape.

## Finding 6 : On Other Parent Responses Towards Securing Their Children's Future

All parents of children with disabilities face the question, "who/what after us/me?"

Legal Guardianship does not cover aspects of long-term care: While legal guardianship provides necessary authority, the question of who will effectively care for the person with disabilities upon the parents' passing remains. This motivates alternative solutions such as:

- a. **Group homes:** The study revealed that the concept of group homes for children with intellectual and developmental disabilities is slowly coming up across the country. These specialized residences are often run by trusts or registered societies with professional care that are mostly parent-led. Some parents envision societies or trusts where families with persons with disabilities co-locate, creating a supportive network and mutual support systems.

CLAPS<sup>42</sup> is a group home (registered under the Tamil Nadu Registration Act) in Tiruvallur, near Chennai. It has been developed by 48 families to house children with ASD and ID within a complex that provides lifelong support and opportunities for positive living, such as vocational activities (housed under a vocational training center run by parents and some caregivers). The home has 48 apartments with 56 rooms for persons with disabilities, allowing them to experience life "without" their parents and enabling a smooth transition after their parent's lifetime.

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<sup>42</sup><https://www.clapschennai.org/>

However, some parents also shared their unease and apprehension about sending their children to group homes.



... to be very frank, I don't want to go there. I don't want to take VN anywhere. Because as a parent, I think nobody's going to give the kind of things that we give VN. And VN has grown up with a certain kind of lifestyle. I am petrified to think of how other places will be. To be very frank. I have gone and seen the autism ashram in Hyderabad. But of course, I went a long time ago. I think, at least, as parents we are sure that we need to look up, we need to keep these provisions ready for VN. Do I want to do it? No, I don't want to. To give you a frank opinion, I hope I don't have to do it. But the unfortunate part is that this is the way to do it.

-VeN, the mother of VN



**b. Trusts to ensure financial security for persons with disabilities:** Our study found that parents, with or without formal guardianship, are proactively establishing private trusts<sup>43</sup> to ensure their child's financial stability in the long run. Furthermore, many parents are unaware of the procedure to draft wills, which facilitate smooth inheritance of property and finances that will serve as a crucial step in securing their child's future.



We haven't made a will. And we don't know how to do that. But we've created a trust. We have three people who are trustees, who are known to us, who are younger than us. That was another thing. We need to have someone who is at least 10 years younger than us.

-VeN, the mother of VN



43 Private trusts are governed by the Indian Trusts Act, 1882 ("Trusts Act"). Under the Trusts Act, to create a testamentary trust, the testator must bequeath all or some of his property under the Will to a person (trustee) to hold and utilize it for stated purposes, for the benefit of one or more persons (beneficiaries). This is a way parents ensure smooth inheritance for their ward with disabilities. The Trustee of the Testamentary Trust can take care of the financial need of the person with disability who would be the beneficiary of the Trust. A testamentary trust takes effect in accordance with the terms of the Will only upon the demise of the testator (the parent/guardian). Till his demise, the testator may amend the terms of the trust as often as he prefers by amending his Will through a document called 'codicil', or by executing a new Will. Upon the demise of the testator, the executor named in the Will must – after probate (as required) is obtained – commence the formalities for constitution and operation of the testamentary trust.



**Finding 7 : Guardianship By Natural Life-cycle**

During the years of transition from childhood to adulthood, parents lack awareness about legal guardianship processes and regarding the rights of persons with disabilities.

**Figure 6** shows a time sequence of legal guardianship for persons with intellectual and developmental disabilities, based on our study findings. The figure reveals that when the child transitions to adulthood, parents are still in the process of transitioning from natural guardianship to legal or no legal guardianship. For many parents, this is because of the lack of awareness of legal guardianship processes under the different acts (i.e., NT Act and RPwD Act) or of persons with disabilities’ rights. After 30 years, parents have taken up guardianship based on the severity of the decision-making impairment of their child under the NT Act. This could also be because many persons with disabilities, now in their 30s, had reached the age of majority when only the NT Act prevailed. Others, particularly those with CP, live independently. Furthermore, our study found that parents (with children above the age of 23) are in the process of setting up trust funds and considering alternative living arrangements.

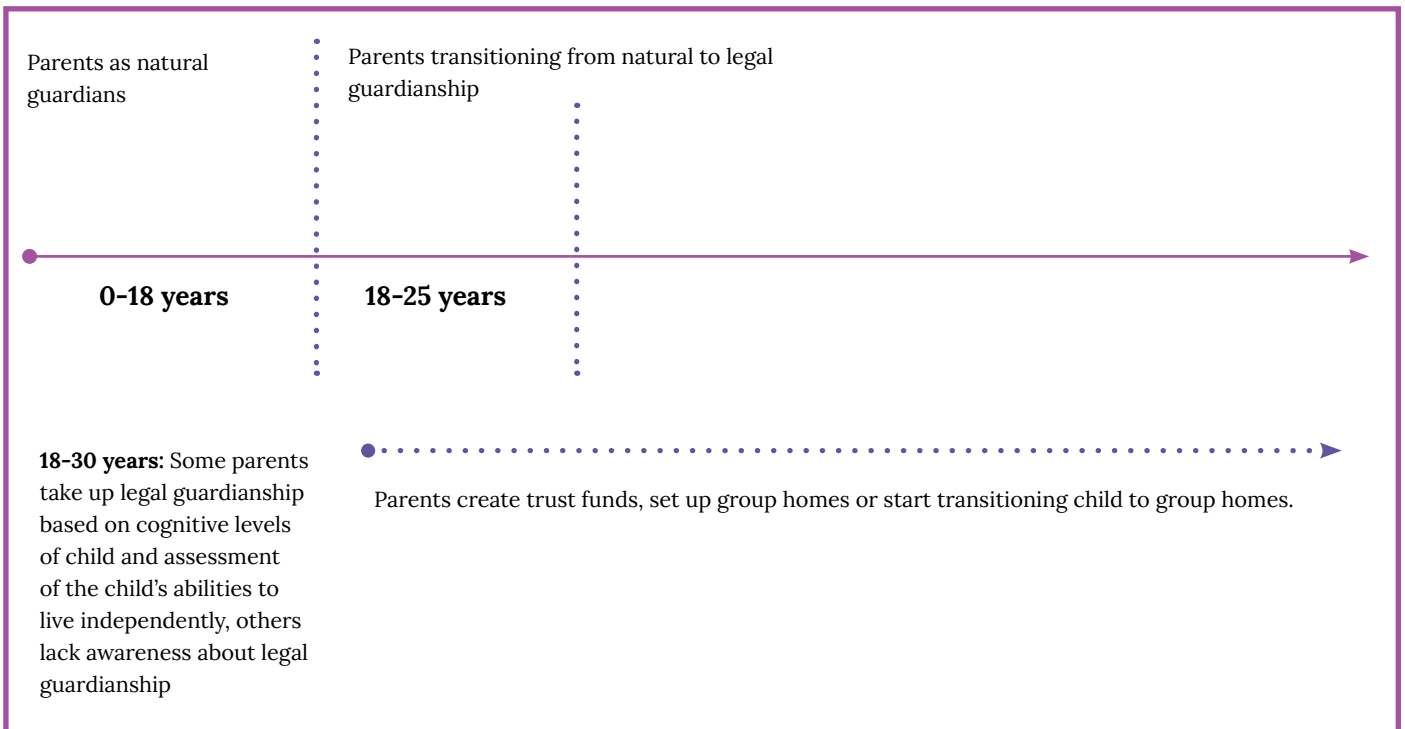


Figure 6: Timeline of Legal Guardianship and Care Mechanisms for Persons with Disabilities

**As per the UNCRPD, “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”<sup>44</sup> Thus, disability is a social construct rather than an inability or lack of capacity at the individual level.**

44 United Nations Convention on the Rights of Persons with Disabilities. (2007). [https://www.un.org/disabilities/documents/convention/convention\\_accessible\\_pdf.pdf](https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf)



**Part 6**

# **Recommendations**



## 8. Recommendations

Recommendation	Reference	Proposal
<p><b>Consolidate guardianship laws towards a new comprehensive legal framework for legal guardianship aligned with the UNCRPD</b></p>		<p>Develop a unified guardianship framework consolidating fragmented laws currently under RPwD Act, NT Act, MH Act and align the framework with Article 12 of the UNCRPD to ensure the recognition of legal capacity for persons with disabilities. This will help overcome challenges when state-wise rules under the RPwD Act have not been notified. In the unified guardianship framework, embed supported decision-making as the guiding principle to uphold the autonomy, will, and preferences of persons with disabilities.</p>
<p><b>Amend the NT Act aligned with the UNCRPD, enshrining principles of legal capacity for persons with disabilities.</b></p>	<p><b>Amendment Reference: Sections 14 and 15 of the NT Act</b></p>	<ul style="list-style-type: none"> <li>a. Revise Section 14 and 15 of NT Act to include explicit provisions for supported decision-making mechanisms, instead of the ambiguous role of the guardian.</li> <li>b. Amend Section 14 to mandate that persons with disabilities themselves should be the primary applicants for guardianship, ensuring their agency remains central to the process.</li> </ul>
<p><b>Standardize adjudicating authority &amp; processes for appointing legal guardian under RPwD Act</b></p>	<p><b>Amendment Reference: Section 14 of the RPwD Act (Rights and Entitlements)</b></p>	<ul style="list-style-type: none"> <li>a. Designate the State Commissioner for Persons with Disabilities (SCPD) as the sole adjudicating authority for guardianship cases, drawing from successful state models like Madhya Pradesh, to avoid ambiguity when no RPwD Rules are notified.</li> <li>b. Introduce detailed rules under Section 14 to establish transparent and uniform procedures for assessing guardianship needs, including case-by-case periodic reviews.</li> <li>c. Acknowledge the spectrum of decision-making capacities through specific guidelines under Section 14, informed by FGDs with persons with intellectual and developmental disabilities (e.g., ASD and ID).</li> <li>d. Formulate rules under Section 14(4) that the duration of limited guardianship must be determined on a case-by-case basis, tailored to individual circumstances and reviewed periodically.</li> </ul>

Recommendation	Reference	Proposal
<p><b>Drive compliance with accessibility provisions under RPwD Act to enable meaningful inclusion and decision-making for persons with disabilities</b></p>	<p><b>Legal Reference: Rule 15 of RPwD Rules</b></p>	<p>Governments (such as state departments/DEPWD, CCPD, Government of India) could drive compliance with Rule 15 of RPwD Rules, which specifies IS 17802 as the standard to be followed for all public and private digital infrastructure. This will ensure that all digital processes for the collection of consent from persons with disabilities are compliant with the prescribed standards of accessibility.</p>
<p><b>Abolish IQ as a barometer for decision-making capacity determination and disability certification</b></p>	<p><b>Amendment Reference: Sections 14 and 15 of the NT Act</b></p>	<p>Medical assessments for those with intellectual and developmental disabilities within the law and policies must go beyond intellectual quotients (IQ) to understand the decision-making capacity of the person with disability.<sup>45</sup> Currently, disability assessments under the RPwD Act (for availing different government schemes and programs) are based on IQ tests.<sup>46</sup> Instead, decision-making assessments need to be contextual, measured over time to ensure stability, and acknowledge individuality of the person with a disability.<sup>47</sup> A decision-making capacity determination, wherein there is a balance between individual autonomy and welfare and well-being<sup>48</sup> before the type of legal guardianship is ascertained, will help balance the autonomy of the person with disabilities and the concerns of the family.</p>

<sup>45</sup>UCL News. (2021, May 20). Decision-making ability identified, independent of IQ. UCL. <https://www.ucl.ac.uk/news/2021/may/decision-making-ability-identified-independent-iq>

<sup>46</sup><https://theprint.in/india/education/1st-india-made-iq-test-tailored-to-the-indian-experience-set-for-launch-this-week/1769609/o> fulfill their obligations. Therefore, a person who does not reside with the person cannot assume the role of a legal guardian as per the NT Act.

<sup>47</sup>[Information and Privacy Commission. (2021). Privacy and persons with reduced decision-making capacity: A guide for public sector agencies. Government of New South Wales, Australia. [https://www.ipc.nsw.gov.au/sites/default/files/2021-11/Guide\\_Privacy\\_and\\_persons\\_with\\_reduced\\_decision-making\\_capacity\\_November\\_\\_2021.pdf](https://www.ipc.nsw.gov.au/sites/default/files/2021-11/Guide_Privacy_and_persons_with_reduced_decision-making_capacity_November__2021.pdf)

<sup>48</sup>Agarwal, & D'Souza. (2021, March). Decision Making for Persons with Impaired Capacity. In Vidhilegalpolicy.in. Retrieved July 31, 2023, from <https://vidhilegalpolicy.in/wp-content/uploads/2021/03/Decision-Making-for-Persons-with-Impaired-Capacity-Full.pdf>

Recommendation	Reference	Proposal
<p><b>Conduct awareness programs to bridge gaps between intent of UNCRPD and lived realities of persons with disabilities</b></p>		<p>Awareness about the concepts of legal capacity, decision-making capacity, limited guardianship and the role of the legal guardian is key to ensuring that the practice matches the UNCRPD provisions. Government programs, augmented by civil society programs, would help raise awareness about the rights and autonomy of persons with disabilities. Such awareness programs need to be initiated with persons with disabilities, parents of persons with disabilities, medical and para-medical service providers (government and private), teachers and special educators (government and private), justice workers (police, prisons, legal aid and courts), banks &amp; insurance companies, digital platforms (government and private), employers (government and private), government and private infrastructure providers (builders, transport services, essential commodity providers, entertainment services) and other service providers across the life cycle of persons with disabilities.</p>
<p><b>Make data about legal guardianship for persons with disabilities publicly available to facilitate research</b></p>		<p>Consolidated and disability-disaggregated data about guardianship prevalence is not available publicly. This is a major inhibitor to the conduct of research to assess the implementation of guardianship laws. A database of de-identified but consolidated and disability-disaggregated data about guardianship prevalence will help researchers understand the translation of laws from theory to practice. This would also incentivise more research on legal guardianship generally, since there is little localised research narratives on the topic, specific to the Indian context.</p>



## **Part 7**

# **Limitations of the Study**



## 7. Limitations of the Study

- **Middle-to-upper-middle-class representation:** The parent and person with disabilities participants interviewed were from the middle-to-upper-middle class residing in urban areas. Therefore, these views cannot be generalized to the views of persons from other strata of society.
- **A majority of parents or guardians represented only the ID and ASD groups:** Except for two parents who took part in FGD 1, all others interviewed for the study had children with ID/ASD. Therefore, the results cannot be generalized to understanding legal guardianship with those with CP, who have differing physical and cognitive capacities.
- **Desirability bias:** There is a possibility of social desirability response bias<sup>49</sup> in this phase of the study. Parents, in particular, understood the reasons for the study, and it is possible that they did not want to sound like they were solely making decisions for their adult children with disabilities. Therefore, parent narratives (to some extent) need to be interpreted with caution. Furthermore, in our study, we have not come across abuse or exploitation by the legal guardian. On the contrary, parents and guardians acted in the “best interest” of the person with disabilities. Further research needs to explore capacity and legal guardianship in cases when there is a chance of exploitation, to provide suggestions for safeguards within the law.
- **Limited stakeholder voices captured:** Phase I of the study focused on persons with disabilities and their parents/guardians. While these voices are crucial to understanding how laws translate into lived experiences, the findings cannot be interpreted wholly based on these voices. Phase II of our study, which includes other stakeholders such as experts and those responsible for implementing laws and policies, will help interpret the findings against the background of the socio-legal structures.

<sup>49</sup>Graeff, T.R. (2005). Response Bias. In K, Kempf-Leonard (Ed.), *Encyclopedia of Social Measurement* (pp. 411-418). Elsevier. <https://doi.org/10.1016/B0-12-369398-5/00037-2>.



**Part 8**

# **Annexures**



## 8. Annexures



## 1. Methodology



A qualitative research method was used to explore the socio-legal relationship between decision- making capacity, legal capacity, and legal guardianship for persons with intellectual and developmental disabilities. We used both individual interviews and focus group discussions (FGDs) to explore these concepts with persons with disabilities, parents/guardians, and experts. Individual interviews were conducted with 8 parents and 1 sibling guardian, 7 persons with disabilities, and 6 experts (total of 22 interviews). In addition, we conducted 2 FGDs with parents (one with 3 parents and the other 14-15 parents) and 1 FGD with persons with ASD and ID (with 9 persons with disabilities) (a total of 3 FGDs). All individual interviews and 1 FGD with persons with disabilities were conducted online. 2 FGDs with parents were held in person in Bangalore. The duration of each of the individual interviews was between 30-45 minutes. FGDs took up to an hour to complete. All interviews were recorded, transcribed, and thematically analyzed.

A convenience sample was chosen based on the networks of EnAble India and Pacta. Below are the details of the sample.

Parents/Guardian					
#	Participant ID	City/Region in India	Taken up legal guardianship	Type of Disability of the Person	Age of the Person with Disability
1	CG	Kolkata	Yes	Down's Syndrome (ID)	28
2	SB	Pune	Yes	ID	39
3	SD	Kolkata	No	ASD	21
4	VeN	Mumbai	No	ASD (Fragile X Syndrome)	23
5	VY	Bangalore	No	ASD	18
6	TG	Chennai	Yes	ID	29
7	SuB	Chennai	Yes	ASD	33

#	Participant ID	City/Region in India	Taken up legal guardianship	Type of Disability of the Person	Age of the Person with Disability
8	AR	Goa	No	ID	24
9	PD	Hyderabad	Yes	Down's Syndrome (ID)	50
10	FGD 1 (3 parents)	Bangalore	Except for 1 parent	CP, ID, and Mental Illness (Schizophrenia)	18-30 years
11	FGD 2 (14-15 parents)	Bangalore	No	Mixed group of ID, not diagnosed, seizure disorder, ASD	13-28 years

#### Persons with Intellectual Disabilities and Developmental Disabilities

#	Participant ID	City/Region in India	Has a Guardian?	Type of Disability of the Person	Age of the Person with Disability
1	AB	Pune	Yes	ID	39
2	KD	Kolkata	No	ASD	21
3	VN	Mumbai	No	ASD (Fragile X Syndrome)	23
4	SP	Bhubaneswar	No	CP	26
5	Dr. AL	New Delhi	No	CP	24
6	RR	Chennai	No	CP	40
7	SrP	Bangalore	No	CP	30
8	FGD 1	Kolkata	4 have a legal guardian, 1 decided not to take up, others are in the process of applying for it	ID and ASD	18 - 30 years

**Experts**

#	Expert ID	Designation	City/Region in India
1	Dr. KR	Developmental Pediatrician	Bangalore
2	SCV	Lawyer	New Delhi
3	AB	Parent Volunteer	Bangalore
4	AH	Founder and Local Level Committee (LLC) Member	Hasan/Hospet, Karnataka
5	Dr. SP	Director, Consultant Psychiatrist	Pune
6	AK	Program Manager, Research Fellow	Pune

**2. Questionnaires****2.1. Persons with Disabilities Questionnaire**

Basic information on the person with disability

1. Your name
2. Your age
3. What gender do you identify with?
4. Who are your family members? Do you have a sibling(s)?
5. What are your educational qualifications?
6. Are you employed? If yes, where? What type of job are you engaged in?
7. What type of disability do you have?
8. Are you diagnosed with a permanent disability?
9. What is the percentage of severity of disability per the RPwD?

Dimensions	Questions
<b>Decision-making capacity</b>	<p>Can you speak about what decision-making means to you? How do you see the term responsibility as an adult?</p> <ul style="list-style-type: none"> <li>• In your opinion, how does one learn to make decisions? Does it come naturally without any practice?</li> <li>• How are people with disabilities shown to make decisions and take responsibility?</li> </ul>
	<p>Can you talk about your childhood experiences in terms of your family dynamics towards you?</p> <ul style="list-style-type: none"> <li>• Did you feel that you were being neglected by your family?</li> <li>• Did you feel that your family was overprotecting you?</li> </ul>
	<p>How did your disability determine the way you were treated in your family?</p> <ul style="list-style-type: none"> <li>• Were you treated differently from your family members, particularly your sibling(s)?</li> </ul>
	<p>How did you exercise your say in your family? Can you talk about your experiences in comparison to other members in your family particularly your sibling(s)?</p>
	<p>As you grew up were you given the opportunity or space to make decisions about your life?</p> <ul style="list-style-type: none"> <li>• Such as food habits, choice of clothes, watching TV or going out with friends, or deciding about your career or even your healthcare options</li> </ul>
	<p>Can you speak about the period when you turned a major or 18 years of age? How did the situation change concerning your decision-making powers and taking responsibility?</p>
	<p>Today in your adult life are your opinions and decisions considered or taken seriously by your family? Do you feel that you have agency over your life?</p>
	<p>Can you talk about the aspects that require your decisions and will today? (Such as partnerships/your personal preferences/finances/property/employment/education?)</p> <ul style="list-style-type: none"> <li>• How does your disability play a role in this?</li> </ul>

Dimensions	Questions
<b>Legal capacity</b>	What do you know about legal capacity and your legal rights? <ul style="list-style-type: none"> <li>• Do you feel you are empowered regarding your rights?</li> </ul>
	Can you speak about your experiences with exercising your legal capacity? <ul style="list-style-type: none"> <li>• From the family perspective</li> <li>• From the judicial system</li> </ul>
	Can you talk about the aspects that require you to exercise your legal capacity? (Such as partnerships/your personal preferences/finances/property/employment/education?) <ul style="list-style-type: none"> <li>• How does your disability play a role in this?</li> </ul>
	Were there instances where you were denied your legal capacity by either the family or court? <ul style="list-style-type: none"> <li>• How did you feel about it?</li> </ul>
	What are the roadblocks to the understanding legal capacities of those with disabilities?
<b>Legal guardian</b>	Do you have a legal guardian? Who is it?
	Can you talk about how you came to have a legal guardian? <ul style="list-style-type: none"> <li>• Socially?</li> </ul>
	What is the legal procedure to get a guardian? <ul style="list-style-type: none"> <li>• Are you aware of the process of getting a guardian? Can you explain it?               <ul style="list-style-type: none"> <li>» How was your experience in obtaining a UDID card?</li> </ul> </li> <li>• Are you aware of the term "limited guardianship"?</li> </ul>
	Tell us your experiences in having a legal guardian. <ul style="list-style-type: none"> <li>• Situations where you felt you were denied your legal rights by the guardian or the legal system</li> <li>• Situations where having a guardian worked</li> </ul>

Dimensions	Questions
<b>Decision-making through a guardian/caregiver</b>	<p>Are decisions taken by your guardian made for you or are you consulted?</p> <ul style="list-style-type: none"> <li>• Can you give some examples?</li> <li>• How does it make you feel?</li> </ul>
	<p>Can you speak about your experiences with exercising your legal capacity?</p> <ul style="list-style-type: none"> <li>• From the family perspective</li> <li>• From the judicial system</li> </ul>
<b>Suggestions to improve</b>	<p>Can you speak about ways we can improve the situation of supported decision-making or independent decision-making both socially and legally?</p> <ul style="list-style-type: none"> <li>• If you think otherwise, do let us know why? Any other information you would like to share that we may have missed out during our session</li> </ul>

## 2.2. Caregiver/Guardian Questionnaire



Basic information on the person with disability

1. Your name
2. Your age
3. Your relation to the person with disability
4. What are your educational qualifications?
5. Who is the breadwinner in your family?
6. What SES would you say you belong in?

Dimensions	Questions
<b>Decision-making capacity</b>	<p>Can you speak about what decision-making means to you? How do you see the term responsibility for an adult?</p> <ul style="list-style-type: none"> <li>• In your opinion, how does one learn to make decisions? Does it come naturally without any practice?</li> <li>• How are people with disabilities shown to make decisions and take responsibility?</li> </ul>
	<p>Can you talk about your experiences of having a child/person with disability in your family? How did that affect the family dynamics?</p> <ul style="list-style-type: none"> <li>• Can you talk about your and your family's attitudes towards the person?</li> </ul>

Dimensions	Questions
	<ul style="list-style-type: none"> <li>• Did the disability determine the way you treated the person with the disability?</li> <li>• Was the person treated differently from other family members, particularly the sibling(s)?</li> </ul> <p>Did the person with disability have a say in your family? Can you talk about these experiences in comparison to other members in your family particularly the sibling(s)?</p> <p>Was the person with disability given the opportunity or space to make decisions about their life?</p> <ul style="list-style-type: none"> <li>• Such as food habits, choice of clothes, watching TV or going out with friends, or deciding about their career or even with respect to your own healthcare options</li> </ul> <p>Can you speak about the period when the person with disability turned a major or 18 years of age? How did the situation change to their decision-making powers and taking responsibilities?</p> <p>Today in their adult life are their opinions and decisions considered or taken seriously by your family? Do they feel that they have agency over their life?</p> <p>Can you talk about the aspects that require the person with disabilities choices, decisions and will today? (Such as partnerships/your personal preferences/finances/property/employment/education/health?)</p> <ul style="list-style-type: none"> <li>• How does their disability play a role in them being given the power to make their own decisions?</li> <li>• How do you see your role in these important aspects of their life?</li> </ul>
<b>Legal capacity</b>	<p>What do you know about legal capacity and the people with disabilities' legal rights?</p> <p>Can you speak about your experiences with them wanting to exercise their legal capacity?</p> <ul style="list-style-type: none"> <li>• From the family perspective</li> <li>• From the judicial system</li> </ul> <p>Were there instances where they were denied their legal capacity by either the family or court?</p> <ul style="list-style-type: none"> <li>• Why was it so?</li> </ul>

Dimensions	Questions
	From the perspective of their guardian/caregiver, what are the roadblocks in the understanding of the legal capacities of those with disabilities?
<b>Legal guardian</b>	Are you their legal guardian?
	Can you talk about how you came to be their legal guardian? <ul style="list-style-type: none"> <li>• Socially?</li> </ul>
	What is the legal procedure to become a guardian? <ul style="list-style-type: none"> <li>• Are you aware of the process of becoming a guardian? Can you explain it? <ul style="list-style-type: none"> <li>» How was your experience in obtaining a UDID card for a person with disabilities?</li> </ul> </li> <li>• Are you aware of the term "limited guardianship"?</li> </ul>
	Can you talk about the aspects that require the person with disabilities to exercise their legal capacity? (Such as partnerships/your personal preferences/finances/property/employment/education?) <ul style="list-style-type: none"> <li>• How did their disability play a role in this?</li> </ul>
	Tell us about your experiences in being the legal guardian. <ul style="list-style-type: none"> <li>• Situations where you felt you denied their legal rights (due to social/legal/ethical dilemmas)</li> <li>• Situations where being a guardian worked.</li> </ul>
<b>Decision-making through a guardian/caregiver</b>	Do you make decisions on behalf of a person with a disability? Or do you consult with them regarding their choice? <ul style="list-style-type: none"> <li>• Why do you do what you do?</li> <li>• Can you give some examples?</li> </ul>
<b>Suggestions to improve</b>	Can you speak about ways we can improve the situation of supported decision-making or independent decision-making both socially and legally? <ul style="list-style-type: none"> <li>• If you think otherwise, do let us know why.</li> </ul>
	Any other information you would like to share that we may have missed out on during our session?



### 3. Legal Capacity and Guardianship Provisions



#### 3.1. Laws Affecting Legal Capacity



**1. Indian Contract Act, 1872:** Section 11 of this Act states that every person is competent to contract if they are of the age of majority according to the law to which they are subject, are of sound mind, and are not disqualified from contracting by any law to which they are subject. Section 12 of the Indian Contract Act, 1872, a person is said to be of sound mind ( for the purpose of entering into a contract) if he is capable of understanding the contract and being able to assess its effects upon his interests.

**2. Indian Succession Act, 1925:** This Act deals with the laws of succession and testamentary matters. Sections 59 of this Act address the capacity to make a will, every person of sound mind not being a minor may dispose of his property by will.

**3. Mental Health Care Act, 2017:** This Act provides for the treatment and care of persons with mental illness and their rights. It deals extensively with capacity and the determination of an unsound mind. Sections of the Mental Healthcare Act, of 2017, address various aspects of capacity and unsound mind, including the right to make decisions, the determination of capacity, the role of advance directives, and the protection of individuals who lack decision-making capacity.

**4. Bharatiya Nyaya Sanhita, 2023:** Section 22 of Bharatiya Nyaya Sanhita, 2023 states that an offence that is committed by a person who, at the time of committing the offence, by reason of unsoundness of mind, is incapable of knowing the nature of the act, or that he is doing what is either wrong or contrary to law, then the Act is not an offense/crime.

**5. Bharatiya Sakshya Adhiniyam, 2023:** Section 124 of Bharatiya Sakshya Adhiniyam, 2023 states that all persons shall be competent to testify unless the Court considers that they cannot understand the questions put to them, or give rational answers to those questions, either because of tender years, extreme old age, disease, whether of body or mind, or any other cause of the same kind.

**6. Code of Civil Procedure, 1908:** Order 32 Rule 15 states that the rules from 1 to 14 (except Rule 2-A) shall apply to persons adjudged to be of unsound mind before or during the pendency of the suit. This Act also states that if a Magistrate conducting an inquiry suspects that the accused is mentally unfit to defend themselves, they must investigate further and have the accused examined by a qualified medical officer (Chapter XXV).

**7. Bharatiya Nagarik Suraksha Sanhita, 2023:** Section 367 lays the procedure in case of an accused being a “lunatic” and Section 368 enlists the procedure in case a person of unsound mind tried before Court. Section 369 allows for the release of a person of unsound mind pending investigation or trial.

## 3.2 Guardianship provisions



Act/ Rules	Section/ rule number	Excerpt
The Rights of Persons with Disabilities Act, 2016	Section 13	<p><b>13. Legal capacity.—</b></p> <p>(1) The appropriate Government shall ensure that the persons with disabilities have the right, equally with others, to own or inherit property, movable or immovable, control their financial affairs and have access to bank loans, mortgages and other forms of financial credit.</p> <p>(2) The appropriate Government shall ensure that the 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.</p> <p>(3) When a conflict of interest arises between a person providing support and a person with disability in a particular financial, property or other economic transaction, then such supporting person shall abstain from providing support to the person with disability in that transaction: Provided that there shall not be a presumption of conflict of interest just on the basis that the supporting person is related to the person with disability by blood, affinity or adoption.</p> <p>(4) A person with disability may alter, modify or dismantle any support arrangement and seek the support of another: Provided that such alteration, modification or dismantling shall be prospective in nature and shall not nullify any third party transaction entered into by the person with disability with the aforesaid support arrangement.</p> <p>(5) Any person providing support to the person with disability shall not exercise undue influence and shall respect his or her autonomy, dignity and privacy</p>

## 3.2 Guardianship provisions



Act/ Rules	Section/ rule number	Excerpt
	Section 14	<p>14. Provision for guardianship.—</p> <p>(1) Notwithstanding anything contained in any other law for the time being in force, on and from the date of commencement of this Act, where a district court or any designated authority, as notified by the State Government, finds that a person with disability, who had been provided adequate and appropriate support but is unable to take legally binding decisions, 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 may be prescribed by the State Government:</p> <p>Provided that the District Court or the designated authority, as the case may be, may grant total support to the person with disability requiring such support or where the limited guardianship is to be granted repeatedly, in which case, the decision regarding the support to be provided shall be reviewed by the Court or the designated authority, as the case may be, to determine the nature and manner of support to be provided.</p> <p>Explanation.—For the purposes of this subsection, “limited guardianship” means 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</p> <p>(2) On and from the date of commencement of this Act, every guardian appointed under any provision of any other law for the time being in force, for a person with disability shall be deemed to function as a limited guardian.</p> <p>(3) Any person with disability aggrieved by the decision of the designated authority appointing a legal guardian may prefer an appeal to such appellate authority, as may be notified by the State Government for the purpose.</p>

Act/ Rules	Section/ rule number	Excerpt
	Section 38	<p>138. Special provisions for persons with disabilities with high support.—</p> <p>(1) Any person with benchmark disability, who considers himself to be in need of high support, or any person or organisation on his or her behalf, may apply to an authority, to be notified by the appropriate Government, requesting to provide high support.</p> <p>(2) On receipt of an application under sub-section (1), the authority shall refer it to an Assessment Board consisting of such Members as may be prescribed by the Central Government.</p> <p>(3) The Assessment Board shall assess the case referred to it under sub-section (1) in such manner as may be prescribed by the Central Government, and shall send a report to the authority certifying the need of high support and its nature.</p> <p>(4) On receipt of a report under sub-section (3), the authority shall take steps to provide support in accordance with the report and subject to relevant schemes and orders of the appropriate Government on this behalf.</p>
The National Trust For Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999	Section 14	<p>14. Appointment for guardianship.—</p> <p>(1) A parent of a person with disability or his relative may make an application to the local level committee for appointment of any person of his choice to act as a guardian of the persons with disability.</p> <p>(2) Any registered organisation may make an application in the prescribed form to the local level committee for appointment of a guardian for a person with disability: Provided that no such application shall be entertained by the local level committee, unless the consent of the guardian of the disabled person is also obtained.</p> <p>(3) While considering the application for appointment of a guardian, the local level committee shall consider—</p> <p>(a) whether the person with disability needs a guardian;</p> <p>(b) the purposes for which guardianship is required for a person with disability.</p>

Act/ Rules	Section/ rule number	Excerpt
		<p>(4) The local level committee shall receive, process and decide applications received under subsections (1) and (2), in such manner as may be determined by regulations: Provided that while making recommendation for the appointment of a guardian, the local level committee shall provide for the obligations which are to be fulfilled by the guardian.</p> <p>(5) The local level committee shall send to the Board the particulars of the applications received by it and orders passed thereon at such interval as may be determined by regulations.</p>
	Section 15	<p>15. Duties of guardian.—Every person appointed as a guardian of a person with disability under this Chapter shall, wherever required, either have the care of such a person of disability and his property or be responsible for the maintenance of the person with disability.</p>
	Section 16	<p>16. Guardian to furnish inventory and annual accounts.—</p> <p>(1) Every person appointed as a guardian under section 14 shall, within a period of six months from the date of his appointment, deliver to the authority which appointed him, an inventory of immovable property belonging to the person with disability and all assets and other movable property received on behalf of the person with disability, together with a statement of all claims due to and all debts and liabilities due by such person with disability.</p> <p>(2) Every guardian shall also furnish to the said appointing authority within a period of three months at the close of every financial year, an account of the property and assets in his charge, the sums received and disbursed on account of the person with disability and the balance remaining with him.</p>

Act/ Rules	Section/ rule number	Excerpt
	Section 17	<p>17. Removal of guardian.—</p> <p>(1) Whenever a parent or a relative of a person with disability or a registered organisation finds that the guardian is— (a) abusing or neglecting a person with disability; or (b) misappropriating or neglecting the property, it may in accordance with the prescribed procedure apply to the committee for the removal of such guardian.</p> <p>2) Upon receiving such application the committee may, if it is satisfied that there is a ground for removal and for reasons to be recorded in writing, remove such guardian and appoint a new guardian in his place or if such a guardian is not available make such other arrangements as may be necessary for the care and protection of person with disability.</p> <p>(3) Any person removed under sub-section (2) shall be bound to deliver the charge of all property of the person with disability to the new guardian, and to account for all money received or disbursed by him.</p> <p>Explanation.—For the purposes of this Chapter, the expression “relative” includes any person related to the person with disability by blood, marriage or adoption.</p>
National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Rules, 2000.	Rule 16	<p>16. Application for guardianship-</p> <p>(1) The application by a parent, relative or registered organisation for appointment of guardian for a person with disability shall be made to the local level committee in Form A.</p> <p>(2) The confirmation of appointment of guardian on such application shall be made in Form B.</p> <p>(3) A quarterly report in the prescribed format shall be given by the local level committee to the Board or to the State level agency authorised by the Board giving particulars of the applications received and orders passed thereon.</p>

Act/ Rules	Section/ rule number	Excerpt
	Rule 17	<p>17. Procedure for removal of Guardian-</p> <p>(1) (i) The local level committee upon receiving an application for removal of a guardian from a parent or a relative of a person with disability or a registered organisation on the grounds specified in clauses (a) and (b) of sub-section (1) of section 17 of the Act, shall appoint a team of investigators consisting not less than three persons.</p> <p>(ii) The team shall consist of one representative of the parent organisation, one representative of the association for the disabled and one Government official associated with disability not below the rank of Assistant Director.</p> <p>(iii) While taking a decision on the appointment of guardian, the local level committee shall ensure that the person whose name has been suggested for appointment as guardian is :</p> <p>(a) a citizen of India;</p> <p>(b) is not of unsound mind or is currently undergoing treatment for mental illness;</p> <p>(c) does not have a history of criminal conviction;</p> <p>(d) is not a destitute and dependent on others for his own living; and</p> <p>(e) has not been declared insolvent or bankrupt.</p> <p>(iv) In case of an institution or organisation being considered by the local level committee for appointment as a guardian, the following guidelines shall be followed :</p> <p>(a) the institution should be recognised by the State or the Central Government;</p> <p>(b) the institution should have a minimum of 2 years' experience in offering disability rehabilitation services including running residential facilities or hostel to the respective 'c' category of persons with disability;</p> <p>(c) the residential facility or hostel for persons with disabilities shall maintain minimum standards in terms of space, staff, furniture, rehabilitation and medical facilities as specified by the Board.</p> <p>(v) The team of investigators while investigating a complaint for assessing the abuse or neglect of a person with disability shall follow the guidelines specified by the Board.</p>

Act/ Rules	Section/ rule number	Excerpt
		<p>(vi) The following Acts of commission or omission shall constitute abuse or neglect on the part of the guardian, namely -</p> <p>(a) solitary confinement of person with disability in a room for longer period of time;</p> <p>(b) chaining of the person with disability;</p> <p>(c) beating or treating a person with disability resulting in bruises, skin or tissue damage (not due to his injurious behaviour indulged by the persons with disabilities);</p> <p>(d) sexual abuse;</p> <p>(e) long deprivation of physical needs such as food, water and clothing;</p> <p>(f) no provision or non-compliance of rehabilitation or training programmes as specified by experts in the field of disability rehabilitation;</p> <p>(g) misappropriation or misutilisation of the property of the person with disability; and</p> <p>(h) lack of facilities or no provision of trained or adequate staff for meeting the training and management needs of the persons with disabilities.</p> <p>(2) The team of investigators shall submit their report within a period of ten days.</p> <p>(3) Upon receiving the report of the investigation team, the local level committee shall take the final decision within the period of ten days on the removal of the guardian against whom the complaint has been received after giving the said guardian an opportunity of being heard.</p> <p>(4) The local level committee shall record in writing its reasons for removal of the guardian or rejection of the application.</p>



Act/ Rules	Section/ rule number	Excerpt
The Mental Healthcare Act, 2017	Section 14	<p>14. Appointment and revocation of nominated representative.—(1) Notwithstanding anything contained in clause (c) of sub-section (1) of section 5, every person who is not a minor, shall have a right to appoint a nominated representative.</p> <p>(2) The nomination under sub-section (1) shall be made in writing on plain paper with the person's signature or thumb impression of the person referred to in that sub-section.</p> <p>(3) The person appointed as the nominated representative shall not be a minor, be competent to discharge the duties or perform the functions assigned to him under this Act, and give his consent in writing to the mental health professional to discharge his duties and perform the functions assigned to him under this Act.</p> <p>(4) Where no nominated representative is appointed by a person under sub-section (1), the following persons for the purposes of this Act in the order of precedence shall be deemed to be the nominated representative of a person with mental illness, namely:—</p> <p>(a) the individual appointed as the nominated representative in the advance directive under clause (c) of sub-section (1) of section 5; or</p> <p>(b) a relative, or if not available or not willing to be the nominated representative of such person; or</p> <p>(c) a care-giver, or if not available or not willing to be the nominated representative of such person; or</p> <p>(d) a suitable person appointed as such by the concerned Board; or</p>

Act/ Rules	Section/ rule number	Excerpt
		<p>(e) if no such person is available to be appointed as a nominated representative, the Board shall appoint the Director, Department of Social Welfare, or his designated representative, as the nominated representative of the person with mental illness: Provided that a person representing an organisation registered under the Societies Registration Act, 1860 (21 of 1860) or any other law for the time being in force, working for persons with mental illness, may temporarily be engaged by the mental health professional to discharge the duties of a nominated representative pending appointment of a nominated representative by the concerned Board.</p> <p>(5) The representative of the organisation, referred to in the proviso to sub-section (4), may make a written application to the medical officer in-charge of the mental health establishment or the psychiatrist in-charge of the person's treatment, and such medical officer or psychiatrist, as the case may be, shall accept him as the temporary nominated representative, pending appointment of a nominated representative by the concerned Board.</p> <p>(6) A person who has appointed any person as his nominated representative under this section may revoke or alter such appointment at any time in accordance with the procedure laid down for making an appointment of nominated representative under sub-section (1).</p> <p>(7) The Board may, if it is of the opinion that it is in the interest of the person with mental illness to do so, revoke an appointment made by it under this section, and appoint a different representative under this section.</p> <p>(8) The appointment of a nominated representative, or the inability of a person with mental illness to appoint a nominated representative, shall not be construed as the lack of capacity of the person to take decisions about his mental health care or treatment.</p>

Act/ Rules	Section/ rule number	Excerpt
		(9) All persons with mental illness shall have capacity to make mental health care or treatment decisions but may require varying levels of support from their nominated representative to make decisions.
		<p>15. Nominated representative of minor.—</p> <p>(1) Notwithstanding anything contained in section 14, in case of minors, the legal guardian shall be their nominated representative, unless the concerned Board orders otherwise under sub-section (2).</p> <p>(2) Where on an application made to the concerned Board, by a mental health professional or any other person acting in the best interest of the minor, and on evidence presented before it, the concerned Board is of the opinion that,—</p> <p>(a) the legal guardian is not acting in the best interests of the minor; or</p> <p>(b) the legal guardian is otherwise not fit to act as the nominated representative of the minor, it may appoint, any suitable individual who is willing to act as such, the nominated representative of the minor with mental illness: Provided that in case no individual is available for appointment as a nominated representative, the Board shall appoint the Director in the Department of Social Welfare of the State in which such Board is located, or his nominee, as the nominated representative of the minor with mental illness.</p>
		<p>16. Revocation, alteration, etc., of nominated representative by Board.—The Board, on an application made to it by the person with mental illness, or by a relative of such person, or by the psychiatrist responsible for the care of such person, or by the medical officer in-charge of the mental health establishment where the individual is admitted or proposed to be admitted, may revoke, alter or modify the order made under clause (e) of sub-section (4) of section 14 or under sub-section (2) of section 15.</p>

Act/ Rules	Section/ rule number	Excerpt
		<p>17. Duties of nominated representative.—While fulfilling his duties under this Act, the nominated representative shall—</p> <ul style="list-style-type: none"> <li>(a) consider the current and past wishes, the life history, values, cultural background and the best interests of the person with mental illness;</li> <li>(b) give particular credence to the views of the person with mental illness to the extent that the person understands the nature of the decisions under consideration;</li> <li>(c) provide support to the person with mental illness in making treatment decisions under section 89 or section 90;</li> <li>(d) have right to seek information on diagnosis and treatment to provide adequate support to the person with mental illness;</li> <li>(e) have access to the family or home based rehabilitation services as provided under clause (c) of sub-section (4) of section 18 on behalf of and for the benefit of the person with mental illness;</li> <li>(f) be involved in discharge planning under section 98;</li> <li>(g) apply to the mental health establishment for admission under section 87 or section 89 or section 90;</li> <li>(h) apply to the concerned Board on behalf of the person with mental illness for discharge under section 87 or section 89 or section 90;</li> <li>(i) apply to the concerned Board against violation of rights of the person with mental illness in a mental health establishment;</li> <li>(j) appoint a suitable attendant under sub-section (5) or sub-section (6) of section 87;</li> <li>(k) have the right to give or withhold consent for research under circumstances mentioned under sub-section (3) of section 99.</li> </ul>



#### 4. Laws Affecting Legal Capacity

Rules Enforced			
Authority given as “either-or designated authority”	No designated authority specified but procedure prescribed (forms given)	Procedure described (Forms given) with designated authority	Designated authority with no prescribed procedure
Telangana (District Court)	Haryana	Chhattisgarh (Local Level Committee)	Maharashtra
Gujarat (District Court)		New Delhi	Madhya Pradesh
Odisha (District Court)		Kerala	Manipur
Punjab (District Court)		Tamil Nadu	Rajasthan
Chandigarh (UT) (District Court)		Assam	Meghalaya
Sikkim(District Court)		Goa	Nagaland
Andaman and Nicobar Island (UT) (District Court)		Himachal Pradesh	Delhi (UT)
Tripura (District Court)			Pondicherry (UT)
Mizoram (District Judge)			Jammu & Kashmir (UT)
Bihar (District Court)			Arunachal Pradesh
Uttar Pradesh (District Court)			Ladakh
			Dadar & Nagar Haveli and Daman & Diu
			Jharkhand
			Manipur ( Given in state circular which cannot be found)

#### Rule Enforcement not Available

Draft given	(No draft available)
West Bengal	Manipur
	Uttarkhand
	Lakshadweep

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