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THE RIGHT TO LEGAL CAPACITY

GUARDIANSHIP LAW, RECOGNITION AND PARTICIPATION IN INTELLECTUALLY DISABLED PEOPLE’S LIVES IN TURKEY

Dr Ezgi Taşcıoğlu & Dr Ezgi Şeref

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The Right to Legal Capacity:

Guardianship Law, Recognition and Participation in Intellectually Disabled People's Lives in Turkey

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This project findings report draws on original research conducted as part of the “In Search of Legal Capacity: Law, Guardianship, and Supported Decision-Making in Intellectually Disabled People’s Lives in Turkey” project, funded by the Economic and Social Research Council (ES/W003945/1) and hosted by the School of Law, Keele University (UK).

We would like to thank our project partner Association of Women with Disabilities for their continuous support to the project.

Our sincere thanks go to organisations and individuals who generously assisted with the project and helped us understand both the challenges and opportunities of supporting legal capacity in Turkey.

An Easy Read summary of the project findings is available on our project website.

We thank People First (Self Advocacy) for their assistance with the Easy Read summary and its translation into Turkish.

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Executive Summary

This report presents findings from the project “In Search of Legal Capacity: Law, Guardianship, and Supported Decision-Making in Intellectually Disabled People’s Lives in Turkey”, funded by the ESRC and hosted by Keele University, UK. Drawing on interviews with 44 participants, including intellectually disabled people, family members, legal professionals, and medical professionals, the project examines how legal capacity of intellectually disabled people is constructed, restricted, and experienced in Turkey, and what conditions are necessary for its meaningful enjoyment.

The project findings are organised in three parts in this report:

First, the report examines how guardianship law operates in practice. It shows that a pervasive discourse of vulnerability, protection, and administrative necessity normalises the restriction of legal capacity of intellectually disabled people. Their mental incapacity is frequently presumed rather than carefully assessed, applied across all areas of life rather than linked to specific decisions, and treated as a permanent legal status. Medical reports are decisive in determining outcomes, while intellectually disabled people are routinely excluded from proceedings that directly affect them. Once imposed, pathways for restoring legal capacity remain extremely limited.

Second, the report examines guardianship in its intersection with care. It shows that guardianship is deeply embedded in everyday family life, most often assumed by mothers as an extension of existing care responsibilities. This intersection of guardianship and care reinforces established patterns of dependency. Extended custodianship, in particular, sustains the assumption that intellectually disabled people are unable to lead independent adult lives and will remain dependent on others. The project also finds that extended parental custodianship is inconsistently implemented.

While guardianship is often justified as necessary for care and protection, the research findings reveal a persistent tension: the concentration of extensive decision-making authority in a single individual through guardianship creates a structural risk environment, exposing the restricted person to risks of abuse, neglect, and harm. Formal safeguards, such as the monitoring of guardians, are weak or inconsistently applied, with limited oversight of how this authority is

exercised. In navigating these tensions, families often come to accept guardianship as the necessary, or at least the least harmful option available.

Third, the report turns to the lived experiences of intellectually disabled participants. Their accounts reveal a clear disjuncture between the socio-legal constructions of their incapacity and the capacity they exercise in everyday life through routines, relationships and diverse modes of communication. Four interrelated conditions emerge as central to the enjoyment of legal capacity: accessibility; access to information and communication; recognition, support, and participation; and the material and social conditions necessary for living an adult life.

Across these domains, participants describe significant barriers. Institutional environments, particularly healthcare and administrative systems, are often inaccessible, disorienting, and difficult to navigate. Information is typically provided in inaccessible formats, and communication practices frequently fail to accommodate alternative modes of expression, with serious consequences for accessing care and support and heightened risks in encounters with criminal law.

At the same time, the findings demonstrate that participation in decision-making becomes possible when individuals are recognised as legitimate interlocutors and appropriately supported. Where interactions are adapted, communication is made accessible, and relationships of trust are established, individuals are able to express preferences and take part in decisions, including in complex institutional settings. Beyond formal decision-making, the findings also emphasise the importance of independent living, employment, and community participation for the enjoyment of legal capacity. Yet opportunities in these areas remain limited, with social life often confined to family or educational settings rather than extending into wider community contexts.

Overall, the findings demonstrate that compliance with Article 12 of the CRPD requires a shift away from diagnosis-based and substitute decision-making approaches towards systems grounded in accessibility, support, participation, and the recognition of intellectually disabled people as equal rights-bearing subjects. Ensuring the equal enjoyment of legal capacity therefore requires not only legal reform, but also sustained transformation of the institutional, social, and political conditions through which legal capacity can be realised in practice.

1. About the Project

Substituted decision-making regimes, including guardianship, have long functioned as a central mechanism through which law and society restrict and undermine intellectually disabled people's right to legal capacity. The adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2006 marked an important turning point in this landscape. By explicitly separating mental capacity, understood as a person's decision-making skills, from legal capacity, defined as the formal ability to hold and exercise rights and duties, Article 12 of the CRPD affirms the equal right of intellectually disabled people to legal capacity. Crucially, it also places a positive obligation on states to provide the support and safeguards necessary for its enjoyment in all areas of life.

Turkey signed the CRPD in 2007 and ratified it in 2009, making the CRPD directly binding in Turkish domestic law under Article 90 of the Constitution. However, the CRPD Committee's first Concluding Observations on Turkey (2019) made clear how far domestic law and practice remain from meeting Turkey's obligations under the Convention. In particular, in relation to Article 12, the Committee highlighted the persistence of a guardianship regime that limits legal capacity on the basis of disability.

Against this backdrop, this project set out to explore the challenges and the possibilities of supporting legal capacity in law and in everyday life in Turkey. Its broader aim is to raise awareness of intellectually disabled people's rights under Article 12 of the CRPD and to contribute to conditions that enable and empower them to enjoy legal capacity in law and society on an equal basis with others.

About the Research

The project draws on new qualitative data generated through interviews with intellectually disabled people, their family members, and professionals working within mental capacity law. In total, 44 participants took part in the research: 11 intellectually disabled people, 15 family members, 8 legal professionals, and 10 medical professionals. Ethical approval was obtained from Keele University's Research Ethics Committee prior to recruitment and data collection.

Participants were primarily recruited through gatekeeper organisations, with snowballing and online methods used to supplement recruitment where appropriate. Informed consent was obtained verbally from all participants and recorded. All interviews were audio-recorded, and where consent was given, video recording was also used in interviews with intellectually disabled participants to support analysis of multisensory forms of communication. Throughout this report, all names we use are pseudonyms, and identifying details have been removed to protect participants' confidentiality and anonymity.

Intellectually disabled participants

From the outset, the project was shaped by an awareness of the systematic exclusion of intellectually disabled people from decision-making and policy-making processes that directly affect their lives. Guided by the principle "Nothing about us, without us," used by disabled people and their organisations worldwide, the research placed intellectually disabled people's perspectives, experiences, and ways of knowing at its centre. This commitment was particularly significant for a project concerned with legal capacity, as it required recognising intellectually disabled people not merely as research subjects, but as capable contributors to debates about their own decision-making.

In this project, we use the term 'intellectual disability' to refer to a broad range of disabilities, including learning disabilities, autism, and other neurodevelopmental disabilities. Participants in this category self-identified as intellectually disabled. In the report, we do not specify participants' diagnoses. This decision was taken to shift attention away from diagnostic categories and towards their lived experience both as individuals and as a collective. Some participants also spoke about mental health conditions alongside their intellectual disabilities. While psychosocial disability is not the primary focus of this project, participants' accounts point to the need for better forms of support where intellectual disability intersects with mental health challenges.

Consistent with the support-based paradigm articulated in Article 12 of the CRPD, a central ethical priority of the project was to create interview environments in which intellectually disabled participants felt safe, respected, and able to share their experiences on their own terms. Where necessary, research materials and practices were adapted, including the use of plain-language information and consent sheets. Participants were offered the option of involving a supporter of their choice both when deciding whether to take part and during the interview itself. Where required, consent was also sought from the guardians of legally incapacitated participants, in accordance with Article 448 of the Turkish Civil Code.

Eleven intellectually disabled adults (aged 18 and over) participated in the study. Interviews were loosely structured to give participants greater control over the direction and form of their narratives. Participants were encouraged to express themselves in ways that felt comfortable to them, including through writing, drawing, or sharing photographs or objects. Particular attention was paid to interactional dynamics, including the role of time, trust, and support in facilitating participation. Three participants were interviewed together with their parents, and one interview involved the presence of a supporter (the participant's father). Conversations focused on participants' everyday lives and experiences across a range of contexts, including education, employment, and interactions with legal, healthcare, and social care systems.

Intellectually disabled participants ranged in age from 19 to 43. At the time of interview, six were unemployed; three were in paid employment (two full-time and one part-time); and two were students. Geographically, most participants were based in the Mediterranean region of Turkey (n=6), followed by the Aegean (n=2), Marmara (n=2), and Central Anatolia (n=1).

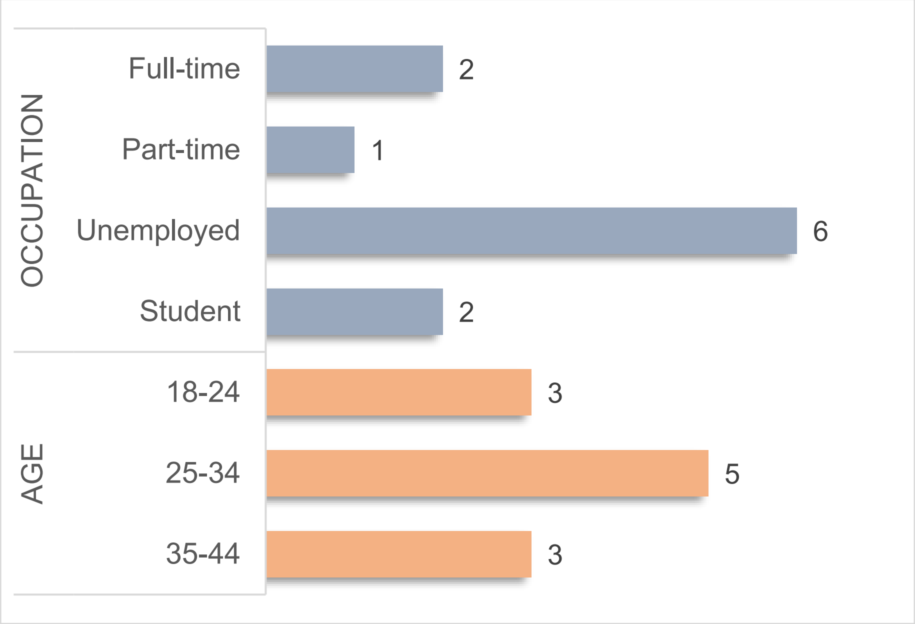

Figure 1.1: Age and occupation of intellectually disabled participants (IDP)

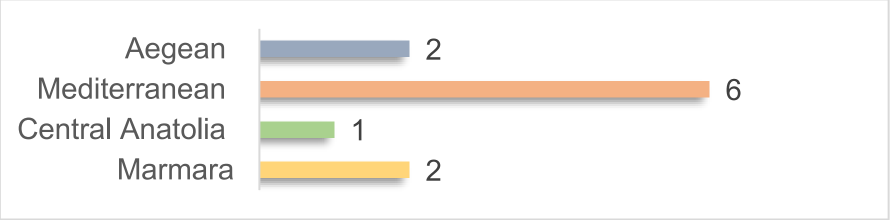

Figure 1.2: Geographical location (IDP)

Family members

Narrative interviews were conducted with 15 family members of intellectually disabled adults. All were parents: 10 mothers and 5 fathers. Interviews began with a broadly open question inviting participants to talk about themselves and their intellectually disabled child[1] with minimal intervention from the interviewer. Follow-up questions were used to encourage further elaboration on issues already mentioned. Where needed, we also raised several themes such as decision-making with and by their disabled child, experiences with the guardianship regime, and broader disability rights.

Family member participants ranged in age from over 35 to over 65. Eight were retired, four were housewives, and three were self-employed. Most were based in the Mediterranean region (n=11), with the remainder living in the Aegean (n=2) and Marmara (n=2) regions.

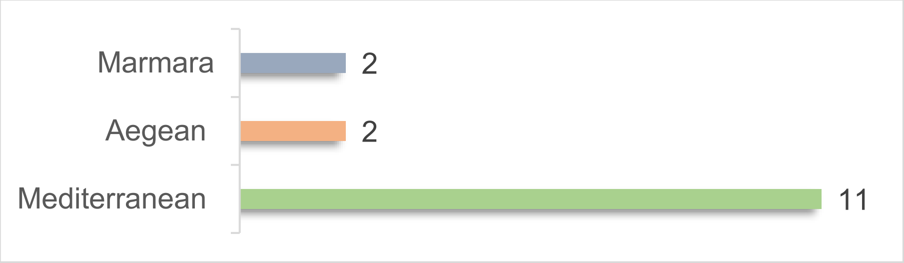

Figure 1.3: Geographical location of family member participants (FMP)

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[1] We use the word ‘child’ here only to indicate the parent-child relationship.

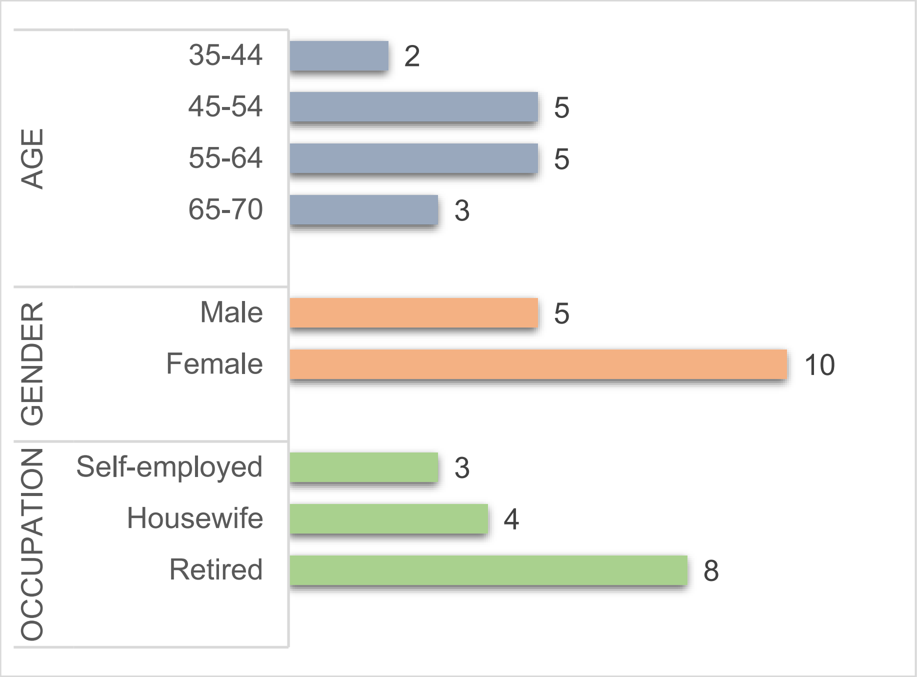

Figure 1.4: Gender, age and occupation (FMP)

Legal professionals

We conducted semi-structured interviews with eight lawyers with experience of working with intellectually disabled people.[2] Participants were initially invited to introduce themselves and reflect broadly on their professional experience of the legal issues faced by intellectually disabled people and their families, including guardianship trials. Follow-up questions were then used to explore specific cases and practices in greater depth, including those relating to participation of intellectually disabled people in legal processes, professional strategies for navigating guardianship proceedings, and systemic barriers within the legal system.

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[2] Originally, we sought to recruit judges involved in the operation of the guardianship regime as research participants. However, our application to the Council of Judges and Public Prosecutors for permission to do so was refused. As a result, we were unable to collect empirical data from judges working within the guardianship system.

Half of the legal professionals identified as women (n=4) and half as men (n=4). Half reported having a disability (n=4). Participants' professional experience ranged from under 10 years to over 30 years. Most were based in the Marmara region (n=4), with the remainder working in Central Anatolia (n=4).

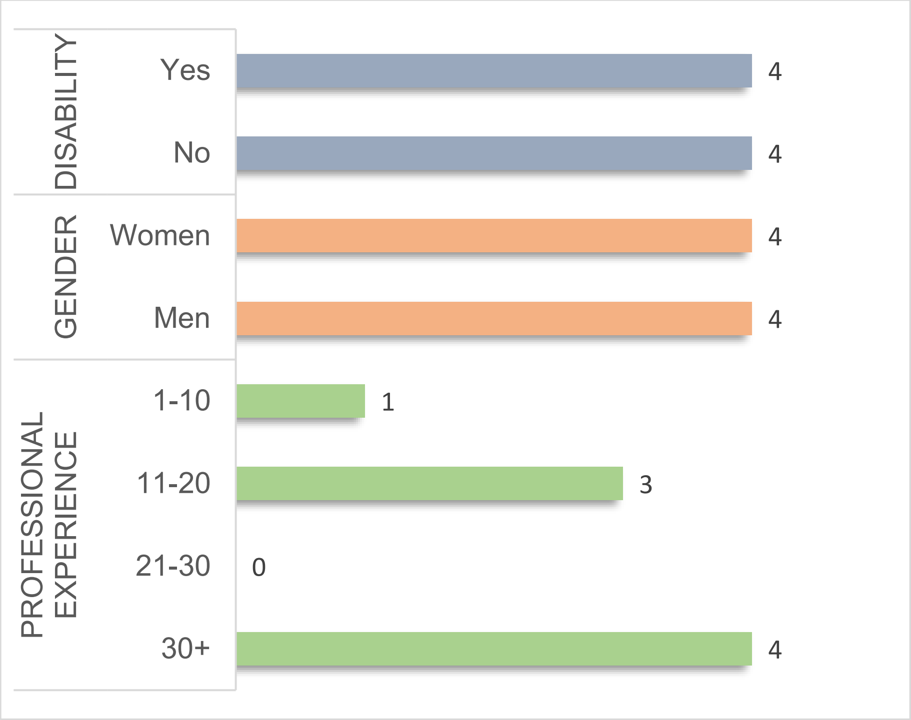

Figure 1.5: Disability, gender and professional experience of legal professional participants (LPP)

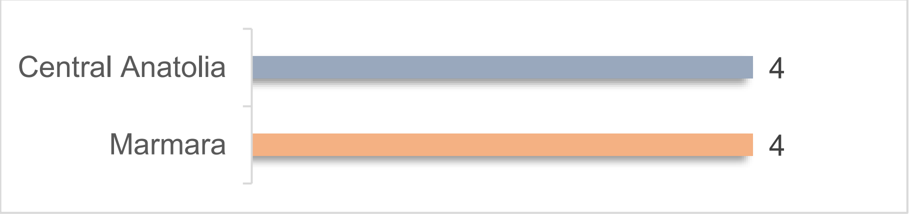

Figure 1.6: Geographical location (LPP)

Medical professionals

Finally, we conducted semi-structured interviews with 10 medical professionals, including eight psychiatrists and two neurologists, who had experience of assessing mental capacity for guardianship proceedings. Interviews began with an overview of participants' professional backgrounds and their involvement in mental capacity assessments. Follow-up questions explored particular cases and practices, including the participation of intellectually disabled people in medical processes, challenges encountered in everyday professional practice and the strategies developed to address these challenges.

Participants' professional experience ranged from over five to more than 30 years. Eight identified as men. Most were based in the Marmara region (n=7), followed by Central Anatolia (n=2) and the Mediterranean region (n=1).

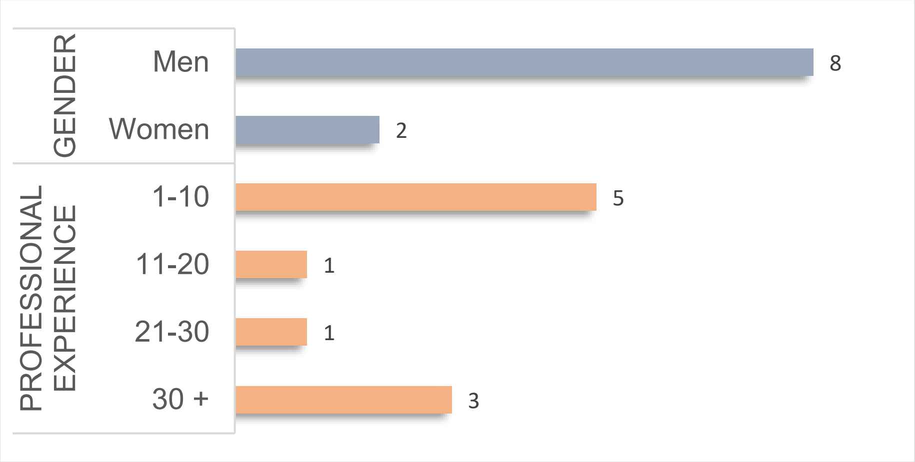

Figure 1.7: Gender and professional experience of medical professional participants (MPP)

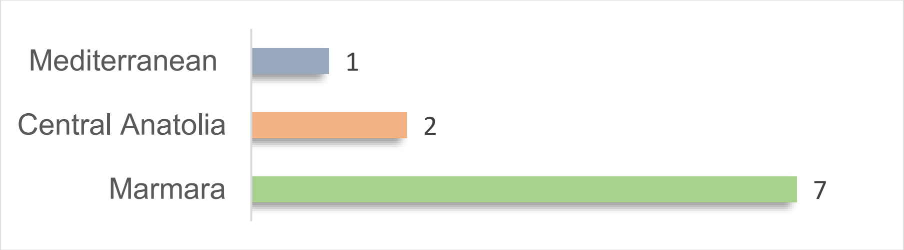

Figure 1.8: Geographical location (MPP)

2. The Right to Legal Capacity

The Convention on the Rights of Persons with Disabilities

This research project is grounded in the UN Convention on the Rights of Persons with Disabilities (CRPD), and in particular in the concept of legal capacity that lies at the centre of Article 12. Adopted by the United Nations in 2006, the CRPD is an international human rights treaty that seeks to promote and secure disabled people's full enjoyment of all human rights and their equal participation in society. As of May 2026, the Convention has been signed by 164 states and ratified by 193 parties, including 192 states and the European Union. By ratifying the CRPD, states commit to giving effect to the rights set out in the Convention through appropriate legislative, policy, and institutional measures. Compliance with these obligations is monitored by the UN Committee on the Rights of Persons with Disabilities, which conducts periodic reviews of state parties' implementation, typically every five years.

The CRPD is widely understood as marking a paradigm shift in legal and social approaches to disability. This shift can be traced along at least two interconnected lines. First, the CRPD is distinctive for the central role played by disabled people in its drafting. Guided by the principle "Nothing About Us Without Us," the drafting process ensured that disabled people's perspectives, priorities, and lived experiences directly shaped the language and substance of the treaty. Secondly, this participatory approach reflected a deeper transformation in how disability itself is understood. The CRPD moves away from paternalistic and protectionist frameworks and towards a rights-based model that recognises disabled people as equal rights-holders and focuses on dismantling discrimination and structural barriers. It affirms disabled people's status as active members of society and calls for their meaningful participation in decisions affecting their lives, whether those decisions concern law and politics or the more ordinary matters of everyday living. In doing so, the CRPD stands not only as a legal instrument, but also a powerful affirmation of the agency, dignity, and equality of disabled people.

The CRPD encompasses a broad spectrum of rights for disabled individuals that span all areas of life. It includes civil and political rights such as the right to life (Article 10), access to justice (Article

13), liberty and security (Article 14), freedom from torture or cruel, inhuman, or degrading treatment (Article 15), freedom of expression and access to information (Article 21), respect for privacy (Article 22), and respect for home and family (Article 23). Alongside these, it includes disability-specific protections, like the right to equal recognition before the law (Article 12), freedom from exploitation, violence, and abuse (Article 16), and the right to live independently and be included in the community (Article 19). The CRPD also secures a wide range of economic, social, and cultural rights, including education (Article 24), health (Article 25), employment (Article 27), adequate standard of living and social protection (Article 28), and participation in political and public (Article 29) as well as in cultural life (Article 30).

Article 12: Equal Recognition before the Law

Article 12 of the CRPD on 'Equal Recognition before the Law' is central to its vision of inclusion and equality. It affirms that disabled people are entitled to be recognised as persons before the law and to enjoy legal capacity on an equal basis with others, with appropriate support and safeguards in place to make this possible.

Legal capacity, in the context of the CRPD, refers to a person's ability to hold rights and responsibilities (legal standing) and to actively exercise those rights and responsibilities (legal agency). Enjoying legal capacity therefore means more than having a legal status as a holder of rights. It also includes being able to act on those rights and to make decisions that are recognised by the law and society.

This understanding of legal capacity is distinct from the concept of mental capacity: **Mental capacity** refers to a person's decision-making skills, which may vary between individuals and may also fluctuate over time for the same person. Legal capacity, by contrast, is a universal human right that belongs to all people. Article 12 makes clear that neither mental incapacity nor intellectual or psychosocial disability can ever serve as a justification for the denial of legal capacity.

Historically, however, disabled people, and particularly those with intellectual disabilities, have frequently been deprived of legal capacity. In some legal systems, this has occurred on the basis of disability status alone (status-based approaches); in others, following assessments of mental incapacity (functional approaches); and in others, by reference to the perceived risks or consequences of a particular decision (outcome-based approaches). Across these different approaches, substituted decision-making regimes have been used to exclude disabled individuals from decision-making about their own lives and to allow third parties make decisions on their behalf.

Article 12 represents a decisive break from these traditional approaches. It explicitly challenges the long-standing practice of linking legal capacity to mental capacity and instead recognises disabled people, including those with intellectual disabilities, as full legal agents who have the right to make their own decisions. In doing so, Article 12 requires states to dismantle substitute decision-making regimes, such as guardianship, and to establish systems of supported decision-making that enable disabled people to enjoy their legal capacity.

There are various ways through which this support can be provided. It may include measures such as simplified communication, adjustments to timeframes for decision-making, or the involvement of trusted supporters, peers, or independent advocates. It may also involve formal arrangements, such as supported decision-making agreements or advance directives. Crucially, for support to be meaningful, it must remain under the person’s control. Individuals must be free to accept or refuse support, and decision-making processes must be protected from coercion, undue influence, or substitution in practice.

Legal Capacity as a Foundational Human Right

Legal capacity allows one to make decisions that have a tangible impact on everyday life, from routine choices, such as spending the day out or going on a holiday, to major life decisions concerning education, employment, or relationships, as well as financial, legal, and medical decisions, including opening a bank account, entering a contract, or consenting to medical treatment. Yet legal capacity is not only about decision-making. At a deeper level, it concerns what it means to be recognised as a human being under the law.

Without legal capacity, a person is positioned as an ‘object’ of law rather than a ‘subject’ who is seen, and responded to, as someone with a history, interests, and aims. This condition has been described as a form of “civil death,”[3] with serious implications for a person’s sense of self and social recognition. The removal of control over one’s life also contributes to the further stigmatisation of disabled people as ‘powerless’ and ‘voiceless’, creating conditions in which confinement, neglect, and abuse can more readily occur.

It is for these reasons that the right to legal capacity is a foundational human right and occupies a central place within the broader architecture of disability rights established by the CRPD. Recognition as a person with legal capacity is foundational to being treated as a full and equal member of society. Where legal capacity is denied, the effective enjoyment of other rights becomes impossible or severely constrained. This includes, among others, the rights to access justice (Article 13), to live independently and in the community (Article 19), to be free from torture or cruel, inhuman, or degrading treatment (Article 15), to vote (Article 29), and to access education (Article 24), healthcare (Article 25), and employment (Article 27).

Since the adoption of the CRPD, the right of disabled people to enjoy legal capacity on an equal basis with others has gained increasing international attention. Growing recognition of the inadequacies of, and rights violations associated with, substituted decision-making regimes, alongside a deeper understanding of the need to support the enjoyment of legal capacity, has prompted legal reform efforts in a number of jurisdictions. Countries such as Colombia, Ireland, Peru and Spain, as well as the Australian state of Victoria, are among those that have adopted legislation aimed at supporting disabled people to enjoy their legal capacity, signalling a gradual yet significant global shift in law and policy.

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[3] Quinn, G. and Rekas-Rosalbo, A. (2016) “Civil Death: Rethinking the Foundations of Legal Personhood for Persons with a Disability”, *The Irish Jurist*: 56 (2016), pp. 286-325.

3. Capacity Law and Practice

Legal Capacity in the Turkish Civil Code

In Turkey, the question of whether intellectually disabled adults can make legally recognised decisions is shaped primarily by the Turkish Civil Code (TCC). At its core, the Code distinguishes between two forms of legal capacity: The first is the capacity to hold rights (*hak ehliyeti*), which every person is granted simply by being a citizen (TCC, Article 8). The second is the capacity to act (*fiil ehliyeti*), which determines whether a person's decisions and actions are legally valid. The Civil Code allows a person's capacity to act to be fully removed if they are found to lack "power of discernment" and are formally placed under restriction.

Functioning as the Civil Code's expression of mental capacity, the concept of "power of discernment" plays a central role in how the law approaches intellectual disability and refers to a person's ability to make decisions that the law is willing to recognise. The Civil Code assumes that everyone has this ability unless they are unable to act "reasonably" because of factors such as "mental illness, mental infirmity, or intoxication" (TCC, Article 13). This means that a person may be deemed to lack power of discernment if they are considered incapable of acting "reasonably" and this incapacity is linked to their psychosocial or intellectual condition.

Article 405 of the Turkish Civil Code provides the framework for the restriction (*kısıtlama*) of capacity to act. This provision applies to people with "mental illness or mental infirmity" who are considered unable to manage their affairs, in need of continuous care and protection, or likely to endanger others. Applications for restriction can be made either by individuals or by public authorities and are decided by the Civil Court of Peace, which acts as the guardianship authority. Crucially, restriction decisions must be based on an official medical board report (TCC, Article 409).[4] Once such a restriction decision is made, the person is classified as "fully incapacitated"

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[4] Turkish law (TCC, Article 429) also provides for legal consultancy (*yasal danışmanlık*), a less restrictive measure intended for individuals who may require assistance with certain legal or financial affairs without being fully deprived of legal capacity. This report does not examine it in detail: it was rarely encountered in

(*tam ehliyetsiz*), and as a general rule, their actions are treated as having no legal effect (TCC, Article 15).

Once a full restriction order is made, the court appoints a guardian to act on the person's behalf. In most cases, priority is given to a spouse or close family member (TCC, Article 414). Intellectually disabled adults who are the children of living parents, however, "remain under parental custodianship" (TCC, Article 419). Extended parental custodianship effectively prolongs parental responsibility beyond the usual age of adulthood.[5]

These provisions show that the Turkish Civil Code does not recognise people who lack power of discernment as individuals who bear legal capacity. Instead, assessments of mental capacity are used to restrict their capacity to act and to justify transferring decision-making authority to others and most often family members, particularly parents in the case of adult children. This has profound consequences for the person placed under restriction. Guardians are authorised to represent the restricted person in legal affairs and to manage their property and financial affairs on their behalf. Certain personal rights, such as marriage, are recognised as non-transferable, and people deemed to lack power of discernment are prevented from exercising these rights altogether. Beyond the civil sphere, Turkish citizens under guardianship are also deprived of the right to vote under the Act on Essential Principles of Elections and Registries of Electors 1961, in direct contradiction with Article 29 of the CRPD, which guarantees the right to participate in political and public life.

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participants' accounts or in the practices described by professionals, and several noted that it is poorly known and largely absent from everyday institutional practice. Applications concerning intellectually disabled people appeared to move directly toward full restriction, with little consideration given to less restrictive alternatives.

[5] Although Turkish law formally distinguishes between ordinary guardianship (*vesayet*) and extended custodianship (*uzatılmış velayet*), both fall within the guardianship provisions of the Civil Code. Our research shows that the boundaries between these arrangements are blurred in both everyday language and legal practice. Reflecting these, we use "guardianship" and "guardian" as umbrella terms for the broader framework of legal restriction and substituted decision-making. Where analytically necessary, we distinguish between "ordinary guardianship" and "extended custodianship." Participants' own terminology is retained in quotation marks. We discuss this distinction in Part 4.

This legal framework sits in clear tension with Article 12 of the Convention on the Rights of Persons with Disabilities, which affirms the right of persons with disabilities to equal recognition before the law. In this research, we wanted to go beyond the letter of the law and to understand how these rules operate in everyday life: how medical and legal professionals interpret and apply them, and how intellectually disabled people and their families experience guardianship and legal capacity in practice. The sections that follow present the key findings of the research.

Restriction Applications

Many of the parents we interviewed had direct experience of applying for the restriction of their intellectually disabled adult child. Across these accounts, decisions to seek guardianship or extended custodianship emerged from a combination of medicalised understandings of disability, protection-oriented concerns, and routine encounters with state bureaucracy.

For some parents, restriction was understood as a necessary and almost automatic consequence of diagnosis of intellectual disability itself. Nilgün, for example, described guardianship as a means of shielding her son from victimisation and criminalisation. Without guardianship, she explained, he would be treated "automatically as other normal individuals" and could therefore face legal consequences for actions that, in her view, he could not fully understand or control. In a related account, she framed restriction as a protective response to perceived limits on her son's ability to exercise rights:

> After the age of 18, because of our children's conditions and diagnoses, they are individuals who have limitations in exercising their rights. If they do exercise those rights, there can be consequences that may harm themselves, their surroundings, or their families. That applies even to those who are highly functioning, as I mentioned. Because these children have neurological differences. […] The same was true for Doğuş as well.

In this account, diagnosis does not merely describe a condition. Rather, it constructs the need for protection as inherent to intellectual disability and positions legal restriction as the only possible necessary measure to provide that protection.

This understanding was reinforced not only through individual reasoning, but also through shared parental norms. Guardianship was frequently presented by parents as a natural expectation attached to parenthood itself. Saniye recalled being told that applying for guardianship was simply what parents of intellectually disabled adults were required to do once their child reached adulthood. Similarly, Ayten described guardianship as something she had come to accept through informal knowledge circulating among families in similar situations: “We also knew that we had to put Bora under guardianship once he turns 18 from the experiences of families with older children than [Bora].”

In many cases, however, parents’ first direct encounter with guardianship system arose through attempts to navigate state bureaucracy after their child turned 18. For many parents, applying for guardianship was closely tied to accessing disability-related benefits and entitlements. Ayten and İsmail, for example, sought guardianship in order to claim disability benefits, such as disability allowances and reductions in vehicle tax (ÖTV). Sezin’s experience followed a different trajectory but was similarly shaped by the presentation of guardianship as a bureaucratic requirement. Sezin explained that she had never heard of guardianship until after her husband’s sudden death. The issue emerged only when the family was required to renounce his inheritance on behalf of their disabled daughter, Esin:

> Because some decisions had to be made on Esin’s behalf. This was because we lost our father suddenly. Tax office debts surfaced […] We didn’t know what was going on, and they burdened us with a lot of debts. So, we filed for renunciation of inheritance […] We also filed for renunciation of inheritance on Esin’s behalf. That was probably when the guardianship issue came up because a guardian needed to be appointed.

In other families, the need for guardianship emerged in the context of passport applications. The intellectually disabled sons of Kemal, Deniz, Cemal, and Buket were all placed under guardianship as part of this process. Kemal described the decision in straightforward terms: “We made that decision with the purpose of getting a passport in case we want to travel or go somewhere.”

The accounts of professionals in our study echoed this pattern. Several lawyers described guardianship as closely intertwined with access to social rights, particularly disability benefits. Beyza, one of the lawyers we interviewed, noted simply: “Guardianship is very common for the

ÖTV benefit in Turkey." Another lawyer, Onur, was more openly critical. In his view, guardianship is often pursued for financial reasons rather than to support disabled people's rights or preferences:

> People actually want the guardianship or to become a guardian for economic reasons. That's something that needs to be recognised. No one in Turkey does it with the mindset of 'let me help this person, let me support them.' It's about economics.

Medical professionals described a similar dynamic in their everyday professional practice. For many of them, discussions about guardianship were routinely linked to informing patients and families about disability-related entitlements. Yakup, a psychiatrist, explained how the process typically unfolded:

> This is how the procedure works in Turkey: If it is a case we are already following, I personally tell my patients that they should benefit from certain rights and entitlements. First, they should obtain a disability report. Based on that disability report, they should file a guardianship case before the court. The guardianship case will come back to us anyway. Then we issue a report stating that, due to their condition, it is appropriate for them to be placed under guardianship, and that is how the guardianship process begins.

Faruk, a senior psychiatrist, offered a similar reflection. In his account, guardianship tends to arise from specific bureaucratic or economic pressures:

> Actually, in our [Turkish] context, there are many intellectually disabled individuals who are part of daily life, traditionally speaking. A lawsuit [for guardianship] is not filed for all of them. […] With intellectual disabilities […] usually, families apply because they are unable to perform certain tasks. They do this to access some of the social rights, like disability allowance, vehicles, or discounts. Otherwise, [intellectually disabled individuals] find their place in life in some way.

Across these accounts, applications for restriction appear less as a carefully deliberated legal intervention and more as a practical, naturalised response to both intellectual disability and institutional demands, circulating through medical diagnoses, parental concerns, and encounters with state bureaucracy. Restriction of legal capacity becomes normalised as a necessity rather than recognised as a profound legal and personal intervention in the life of the intellectually disabled adult.[6]

Assessments of Power of Discernment

Once a restriction application is submitted to the Civil Court of Peace, whether by an individual or a public authority, the court orders an expert report to evaluate the intellectually disabled person's power of discernment and to determine whether appointing a guardian is necessary. Under the Civil Code, this report must be prepared by the health board of an authorised public hospital (TCC, Article 409).

In practice, this assessment process is treated as a highly specialised domain. Responsibility for evaluating power of discernment rests overwhelmingly with psychiatrists. As Faruk, a psychiatrist in a university hospital, put it: "Psychiatric examination is fundamental [in Turkey]." Faruk explained the central question guiding these evaluations in these terms: "Is there or is there not a mental impairment that significantly disrupts decision-making capacity? This is our primary consideration."

Medical professionals described the assessment as a multi-disciplinary process, involving not only medical experts but also collaboration with psychologists, social workers, and family members. Faruk outlined the typical procedure in detail:

> First, the person is examined. If the person has given consent, their family members are contacted due to their care relationship if they are available. Then, assessments are carried out. Psychometric assessments are conducted by psychologists. If there is a suspicion of mental disability or retardation, relevant tests are applied. If there is a suspicion of a pervasive developmental disorder present in the history, psychologists apply appropriate tests for this. Social workers also perform social assessments. Once these are all concluded, the tests are sent to the doctor who

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[6] A comparable logic of assumed incapacity has been challenged against a Union of Turkish Notaries circular which required literate blind people to have two witnesses for notarial transactions. Following a legal challenge, the Council of State annulled the circular, a ruling upheld on appeal on 21 May 2025.

> make an evaluation. […] Along with all of this, the person is referred to the health board. The health board then evaluates the person. They conduct another examination. Based on the examination findings and the results of the assessments, they make a decision.

The holistic and multidisciplinary nature of the assessment was seen important in enabling a more contextualised and time-specific evaluation of the person's decision-making abilities. Mehmet, another psychiatrist involved in power of discernment assessments regularly, similarly emphasised the importance of gathering extensive documentation and drawing on multiple professional perspectives:

> When making a decision, we try to strengthen the evidentiary basis as much as possible. We want the decision to be as healthy as possible. For that reason, we seek support from different professionals. Not only from medicine, but also from psychology, social assessment, and similar fields, and we try to make the decision in that way. Sometimes there are very interesting cases. We may request information from unexpected places, such as military service records, something the person did in the past, or even from a fire brigade organisation.

In principle, power of discernment assessments by medical professionals are meant to provide courts with objective, expert evidence. Some medical professionals strongly emphasised this scientific ideal. Faruk described their objective as "to scientific evidence grounded in objective and scientific foundations and data, that is, through both clinical examinations and internationally recognised tests, as well as tests validated in Turkey."

Others were more cautious about claims of objectivity. Fahri acknowledged that outcomes can vary depending on who conducts the assessment: "What I mean is, the power of [discernment] can vary depending on the judgment of the person making the evaluation." Mehmet also reflected on the "grey areas" inherent in these decisions, illustrating this with a case involving a young intellectually disabled woman whose mother opposed her wish to marry. The case, he suggested, exposed the limits of clear-cut distinctions between capacity and incapacity:

> But aren't there grey areas as well? As you were speaking, I remembered a case. We had a young woman from Ordu with mental retardation (*mental retardasyon*).

> Her mother didn't allow her to get married, and somehow there was constantly an appeal to the court. Now, the girl wants to get married. It is borderline. If she killed someone, we would not be able to say she lacked the capacity to act, but when it comes to marriage, we say no, she cannot marry. And yet she is clearly heading into a situation where she is being exploited, beaten, and even sells her though I shouldn't exaggerate. The mother is screaming there, but the girl, even though it might seem illogical to us, is going to make that decision for her own life. So things are not entirely black and white here; there are cases where many shades of grey exist, and we do encounter them. In such situations, can we end up making decisions, consciously or unconsciously, as if the person were our own daughter or sister? Honestly, that is a bit tricky.

Despite acknowledging these dilemmas, Mehmet ultimately returned to the language of objectivity, emphasising that they "endeavour to act objectively, adhering to the principle of impartiality inherent in the role of the expert witness," and "to provide the necessary services to citizens without exceeding our established boundaries or being guided by our own mindset."

Ambiguities in capacity assessments are not resolved in a vacuum. Rather, they are mediated through a pervasive discourse of vulnerability and protection that closely mirrors the protectionist reasoning articulated by parents and frames restriction as necessary. Medical professionals consistently invoked anticipatory risks, such as fraud, abuse, financial mismanagement, sexual exploitation, and criminal liability as reasons to err on the side of mental incapacity for intellectually disabled people. Kaan, a psychiatrist, articulated this position explicitly in professional terms:

> In our routine practice, particularly in cases of mental deficiency, mental retardation, likewise autism and other developmental disorders, if we feel that there are risks which could lead to negative consequences for the person in relation to their capacity to act, or risks that could cause harm to their relatives, we may provide guidance and recommendations to family members in this regard. This is for the protection of both the patient and their relatives. Especially where the person is considered to be below a certain level, we tend to direct them towards guardianship authorities.

This linking of mental incapacity, vulnerability and dangerousness is further intensified by institutional constraints that shape how assessments are conducted. Medical professional participants consistently pointed to severe time pressures and overwhelming caseloads, particularly in state hospitals (as opposed to university hospitals). Yakup, who works at a state hospital, contrasted the time required for a careful assessment with the realities of daily practice:

> Let me put it this way. It's not about the process, but we are currently carrying out this duty at a state hospital. Normally, for such a case, the time allocated should be at least six hours, provided we have no prior information. This would require us to see the patient for one hour on different days. However, in a state hospital, even our health boards sometimes deal with 40 patients a day, and there are instances where it reaches 70-80 people. [...] Naturally, our expert witness duties end up being somewhat superficial. They are not very solid.

Mete, a psychiatrist employed at a university hospital, echoed similar concerns about the pressures created by workload and time constraints, particularly for clinicians working in provincial regions, and how these conditions shape the quality of mental capacity assessments in practice: "When we speak with our colleagues who are on mandatory service in the peripheries, they are required to examine 120 patients a day. […] Therefore, I do not believe the decisions made in these hospitals are as healthy as those made here."

Faruk similarly emphasised how institutional capacity, staffing, and specialisation structure assessment practices on the ground. In many settings, he explained, assessments of power of discernment are conducted not by forensic psychiatry specialists but by generalist psychiatrists working under intense time pressure:

> Most places don't have separate specialised [forensic psychiatry] clinics, and there are no doctors working in this field. These assessments are generally carried out by psychiatrists. In such cases, a situation like this may also arise. General outpatient clinics are extremely busy. Appointments are very crowded. Doctors see a large number of patients during the day. Among all those patients, it is not always possible to conduct evaluations of the kind I described. I mean, they can probably make a quick decision and assessment on very clear cases, but for complex cases, a thorough evaluation is not possible. Therefore, they mostly refer patients to other

> institutions, for example, to university hospitals or to the Forensic Medicine Institute. Social workers are not available everywhere. Or even if they are, they may not have experience with these kinds of cases. […] As a result, the burden on our hospitals increases, meaning the first appointment we can offer gets delayed. The burden on the Forensic Medicine Institute also becomes heavy. In other words, there is no perfect system in place.

These accounts point to a structural context in which assessments are routinely conducted under significant pressures, with limited time, resources and expertise to support careful, individualised evaluation. Yet they reveal not only the challenges for assessing power of discernment through clear, standardised procedure, but also the hierarchical organisation of medical, and particularly forensic psychiatric expertise in Turkey. Assessments move along an institutional ladder: from overcrowded state hospitals staffed by generalist psychiatrists, to university hospitals with specialised forensic psychiatry departments, and ultimately to the Forensic Medicine Institute as the final arbiter of mental capacity determinations.

This hierarchy has significant implications for how power of discernment of intellectually disabled people is assessed in practice. Faruk's reference to "very clear" cases above is particularly revealing in this regard. Across our interviews, what counted as an "easy" and "clear" case was one in which the presence of an intellectual disability diagnosis was treated as sufficient evidence of lack of power of discernment, and therefore of a lack of capacity to act. For intellectually disabled people whose cases are viewed as "clear" rather than "complex," assessments are often conducted at the lowest institutional level, where time pressures are most acute and diagnostic shortcuts most likely. Mehmet put it in this way: "Generally, for autistic individuals or those with what is described as 'mental or intellectual deficiencies,' we tend to take the view that they lack capacity to act."

While a decision- and time-specific approach is at least attempted in relation to mental health conditions, this was rarely described as the case for intellectual disability. Mental incapacity of intellectually disabled people is generally presumed rather than examined, applied across domains of life rather than assessed in relation to specific decisions, and fixed as an enduring legal condition treated as the inevitable consequence of intellectual disability itself.

Restriction Proceedings

Although restriction cases are formally handled by the courts, our findings show that, in practice, they revolve around medical expertise. Doctors, especially psychiatrists, occupy the central position in deciding whether a person should be restricted and placed under guardianship. This was also how medical professional participants understood and communicated their own role. Notably, many did not frame their task as assessing “power of discernment,” the concept used in the Civil Code to denote mental capacity. Instead, they spoke of evaluating a person’s “capacity to act.” This shift in language is important. It signals how medical judgment does not merely contribute evidence for judicial consideration but frequently settles the core legal question in advance.

Lawyers in our study confirmed this. They repeatedly described the medical report as the decisive element in legal proceedings and often described guardianship decisions as being made “on the basis of the file”. As one lawyer, Onur, put it: “In Turkey, what happens is this: you get a medical report. Should the person be placed under guardianship or not? That’s it. If yes, then fine. After that, nothing.” Another lawyer, Şeyda, explained that “that small phrase written at the bottom of the report saying ‘it is appropriate for the person to be placed under guardianship’ is what effectively settles the whole matter.” These accounts suggest that, in many cases, the medical report functions not merely as an expert opinion submitted to the court, but as the decisive element effectively determining the final outcome. Beyond the information contained in the medical report, there appears to be little or no further judicial examination regarding the disabled person’s decision-making capacity or of the necessity of appointing a guardian. Şeyda added:

> There isn’t really any judicial assessment or evaluation going on. It’s very much handled on the basis of the file. If the situation is one where the parties are satisfied, so to speak, the buyer is happy and the seller is happy, it proceeds almost entirely through the file.

The centrality of medical documentation coincides with the systematic absence of the intellectually disabled person from the legal proceedings. Although the Turkish Civil Code permits judges to hear the person subject to a restriction order, this is framed as discretionary and as a clinical judgement: “the judge *may* hear the person in light of the medical board’s opinion” (Article 409, emphasis ours). In practice, this discretion is routinely exercised in favour of exclusion. Research participants told us that guardianship decisions were routinely made without the person being present, and sometimes even without family members present. Saniye described what happened when her family went to court for his son's guardianship trial:

> We couldn't even get into the courtroom. We waited and waited, but the time never came. There was quite a long queue. They said our case is scheduled for later in the day. So, we decided to go to the school and come back. When we returned, the trial was all over, it had finished. They had already made a decision. They said, 'Your presence wouldn't have made any difference. The decision would have been the same.'

Experiences like this show how the knowledge and perspectives of intellectually disabled people, and of those of their supporters and families, are treated as irrelevant in the guardianship proceedings. Instead, the medical report occupies the centre of the judicial process. It does not simply provide evidence; it effectively displaces the person whose legal capacity is at stake and stands in for the person, speaking for, and instead of them. Ayten reflected on this when speaking about her son's case: "I didn't even take Bora with me. The judge didn't want to see him. It was enough for me to go alone and have the [medical] report in hand."

When asked where disabled people sit in guardianship proceedings, Şeyda gave a striking answer: "Right at the centre but as a completely ineffective element." Her remark captures the core tension that runs through our findings. Intellectually disabled people are the focal point of guardianship cases, yet they appear only as objects of assessment rather than as actors or equal participants whose views, preferences, or experiences carry weight in the process. Their absence from the legal proceedings is routinised through the systematic prioritisation of medical documentation over lived experience, and expert opinion over personal voice. The disabled person remains nominally at the centre of the proceedings while being excluded from them, eclipsed from the very decision about the restriction of their legal capacity.

These dynamics are further entrenched by the way diagnosis collapses into permanent mental incapacity. The guardianship regime reflects across law, medicine, and family practice a shared assumption that a diagnosis of intellectual disability constitutes sufficient evidence of incapacity, and that mental capacity of an intellectually disabled person will not "return" or undergo meaningful change in adulthood because the condition is understood as permanent and non-curable. Reflecting this logic, lawyer Eda observed that the lifting of restriction orders is “not something that is commonly encountered in practice, because these are not conditions that can be cured.”

This assumption is reinforced by the legal difficulty of overturning restriction orders. The Turkish Civil Code suggests that capacity to act can only be restored when an official medical board report finds that the reason for the incapacitation no longer exists. (Article 474). This can prove quite difficult for intellectually disabled people whose legal incapacitation is based on what is regarded as a permanent condition. Şeyda offered a more critical account of how the burden of proof operates in practice:

> If I want to have this guardianship order lifted, the burden of proof is placed upon me. I have to prove that there is no longer a reason for me to be under guardianship. […] I am expected to prove that this diagnosis no longer exists, which, technically speaking, is not possible unless the diagnosis was wrong in the first place.

In this way, diagnosis does more than describe a clinical condition across legal, medical, and familial practices. It transforms intellectual disability into a permanent marker of incapacity, foreclosing meaningful opportunities for support or the restoration of legal capacity.

4. Guardianship, Care and Vulnerability

Guardianship and Extended Custodianship in Practice

Once the capacity to act is formally restricted, the restricted individual is placed either under guardianship (*vesayet*) or, where parents are alive and available, under extended parental custodianship (*uzatılmış velayet*) (TCC, Article 419). Both arrangements transfer significant decision-making authority to others, yet they differ in their legal structure, duration, and mechanisms of oversight.

Under ordinary guardianship, guardians are required to keep an inventory (*defter*) of the restricted person's assets (TCC, Article 438) and submit accounts to the guardianship authority for review at regular intervals and at least once a year (TCC, Article 454). The Civil Code further subjects many significant decisions to judicial authorisation and supervision. Acts such as the purchase or sale of property, initiating legal proceedings and changes of residence of the restricted person require permission from the Civil Court of Peace (Article 462), while matters such as adoption, inheritance disputes, or contractual arrangements for lifelong income or care additionally require approval from the supervisory authority, namely the Court of General Jurisdiction (Article 463).

Alongside this ordinary guardianship regime operates the distinct but closely related institution of extended custodianship. Under Article 419 of the Civil Code, intellectually disabled adults with living parents are deemed to "remain under custodianship," effectively extending parental authority beyond the age of majority. Unlike ordinary guardianship, which is granted for renewable two-year periods and is formally subject to periodic judicial review (TCC, Article 456), extended custodianship typically remains in force unless terminated by a court decision as a protective measure (TCC, Article 348). Moreover, many of the accountability and oversight mechanisms applicable to ordinary guardianship are relaxed or removed altogether in extended custodianship. Parents with extended custodianship regain powers closely resembling those they held while the restricted person was a child, including managing bank accounts, withdrawing benefits, and making everyday decisions without the same requirements of formal inventories, financial accounting, or repeated court supervision.

For many parents we interviewed, extended custodianship emerged as a practical response to the administrative burdens and ongoing judicial oversight associated with ordinary guardianship. This was articulated particularly clearly by Nilgün, who drew on her experience both as a mother and as a retired lawyer. She described how families encounter significant practical obstacles once an ordinary guardianship order is imposed: the requirement to renew decisions periodically, notify the guardianship authority of transactions, and seek judicial permission even for relatively routine matters. In response to these difficulties, she explained, she had increasingly begun to "steer families towards extended custodianship instead." As she put it:

> With this arrangement, our authority to act in relation to our children's rights has effectively been expanded. […] We are now continuously our child's legal custodian, just as before the age of eighteen. This is the framework we are operating within now. For that reason, when making decisions about Doğuş, this custodianship decision has really eased my hand.

In this sense, extended custodianship was valued by parents precisely because it reduced administrative burdens, minimised judicial scrutiny, and granted them broader and more continuous authority over the lives of their adult children.

At the same time, participants' accounts revealed how this arrangement was also underpinned by assumptions about the permanence of intellectual disability and, by extension, enduring mental incapacity. Nilgün continued: "After a certain age, these children have already completed their mental development. After the age of 18, there is no possibility that they will suddenly show a new developmental leap and return to what is considered normal." Within this framing, the continuation of parental authority appears as a natural and inevitable consequence of intellectual disability. Yet this continuity comes at a significant cost for the intellectually disabled adult placed under restriction. While the arrangement simplifies legal and administrative processes for parents, it simultaneously entrenches the assumption that intellectually disabled adults inherently lack the capacity to act and normalises their treatment as minors for the purposes of law.

Our research further found that, in practice, the distinction between guardianship and extended custodianship is often blurred, inconsistently applied and poorly understood even by those responsible for enforcing it. The formal legal labels attached to these arrangements (*vasi* and *veli*) do not translate neatly into everyday usage. Participants routinely referred to the process as “guardianship” (*vesayet*) or to their roles as “guardians” (*vasi)*, including when describing situations that, in legal terms, amounted to extended custodianship (*velayet* and *veli*). This is understandable as guardianship operates as the broader legal framework through which both restriction and appointment of a substituted decision-maker are established in the Turkish Civil Code. Ordinary guardianship and extended custodianship rest on the same legal foundations and follow the same procedural route. The distinction between the two arises only at the point of appointment, depending on whether a parent is available to assume the role. In daily life, this formal distinction is often overshadowed by the shared logic and procedure of restriction and substituted decision-making that structures both arrangements.

Importantly, however, the permeability of both categories was not confined to everyday language. It was also mirrored in judicial practice. Sezin, a mother, for example, was initially appointed by the court as an ordinary guardian and told that the order would need to be renewed. When she later returned to court upon the order’s expiry, it was extended indefinitely. Uncertain about the legal distinctions, she said that the initial renewal requirement felt both burdensome and meaningless: “Our children’s situation doesn’t change.”

Kemal recounted a similar experience, illustrating the inconsistent application of these arrangements in practice. Despite having been granted extended custodianship, he was repeatedly required by the judge to seek court permission for transactions that should have fallen within parental authority. Only after consulting a lawyer and a notary did he learn that, as a custodian rather than an ordinary guardian, no such permissions were in fact required:

> It turns out that because I was appointed as the custodian (*veli*), I didn’t need to ask them for permission at all. […] I didn’t even realise I was a custodian. I thought I was a guardian (*vasi*). After that I showed the decision to a lawyer and a notary and asked what we could do. They said, “You don’t need to bother with any of this.” But only after I’d gone through the difficulty five times.

Care, Gender, and the Normalisation of Guardianship

Among the fifteen parents we interviewed, the adult children of twelve were fully restricted and placed under extended custodianship, whereas the children of three were not subject to any formal restriction of legal capacity. Guardianship was generally understood by the first group of parents not necessarily as a withdrawal of rights, but as a means of protection and continuity of care. It enabled them to act in what they understood to be their child's best interests. As Nilgün put it, a parent is someone who strives "to do what is best and most right for their child [...] and to act as the advocate of their child's rights."

Across these accounts, guardianship was rarely experienced among parents as a distinct legal role requiring deliberation. Instead, it was understood as a natural extension of existing caregiving relationships. This was articulated most starkly by Buket, who described guardianship as largely unnoticeable in light of her maternal role: "So nothing really changed in my life [with guardianship]. Everything continues as before. I'm already his mother, so I'm his guardian in every sense anyway." In this account, guardianship follows almost automatically from motherhood. Legal appointment as guardian does not introduce a new form of authority so much as formalise what is already assumed to exist.

This understanding shaped how the role of guardianship was distributed within families. In most families, it was mothers who were recognised as the primary carers, and this caregiving role translated into guardianship. Of the twelve parents whose children were under extended custodianship, eleven were mothers and only one was a father.

Although deeply shaped by gendered expectations of care, parents described this pattern as both practical and self-evident. Because mothers were already responsible for everyday care, education, and engagement with services, families tended to view maternal guardianship as the most appropriate and least disruptive option. As Ayten put it: "They ask you [at the court] who wants to be the guardian. We had discussed this with my husband. Because I generally take care of Bora's education and so on, we decided that I should be his guardian." İsmail described a similar process, noting: "we thought, who will be [our daughter's] guardian? Because the mother is much more closely involved with her, we said 'the mother', and that's how her mother became her guardian." The legal role followed the gendered division of care in everyday life.

Consistent with this framing, guardianship featured only marginally in mother's descriptions of daily routines. Several of them struggled to recall moments when the legal status of guardianship became salient at all. Acting as her son's guardian, Ayten explained that she rarely thought about the role, which only surfaced "when an official decision has to be made in Bora's name." For others, guardianship barely registered as a distinct role. Ela remarked that, despite years of disability advocacy, guardianship had never been central to her thinking or practice as both a lawyer and a mother: "I have never really sat down and worked specifically on guardianship. But I approach it more in terms of care systems, not just guardianship alone. Or rather, when I say care systems, I mean care and support systems."

The experiences of professional guardians cast this apparent invisibility of guardianship in a different light. Eda, a lawyer who routinely acts as a professional guardian, described a role that extends far beyond formally prescribed expectations. Although she spoke as a professional rather than a family member, the responsibilities she described closely mirrored those associated with maternal care: constant availability, emotional resilience, logistical coordination, and responsibility for bodily needs alongside legal and financial matters. The expectation of what she described as being "on alert 24 hours a day" echoes the gendered norms of care that structure family-based guardianship, where mothers are routinely positioned as the default and enduring caregivers:

> You don't have the option of saying 'I'm no longer dealing with this.' Sometimes you can say that even to your family—but in this role, you can't say that. […] I arrange for their nappies to be bought, I sign when they go to hospital, I organise ambulances when necessary. So this is never just one task. There are countless things you can't foresee. Personal matters and legal matters.

Taken together, these accounts reveal a striking asymmetry. Within families, guardianship is absorbed into the fabric of care and rendered largely invisible through its alignment with maternal responsibility. For professional guardians, by contrast, the same role is experienced as all-consuming and impossible to suspend. Yet both are shaped by the same underlying assumptions and expectations: guardianship is imagined and practiced not simply as legal authority, but as a continuous form of care that is deeply gendered.

These accounts also illuminate how guardianship functions not only as a mechanism for transferring decision-making authority from the intellectually disabled person to the guardian, but also for cementing responsibility for care in the figure of the guardian. In this sense, guardianship emerges not only as a regime of substituted decision-making, but also as part of a broader redistribution of care from public institutions to families, and most often to women.

Neglect, Abuse, and Oversight

The normalisation of guardianship as a form of care is closely bound up with a pervasive discourse of vulnerability and protection. Intellectually disabled adults were routinely described across participant groups as vulnerable and exposed to a range of risks, e.g. fraud, deception, financial mismanagement, sexual exploitation, and legal liability. Within this framing, guardianship is understood not simply as a legal response to impaired decision-making, but as a protective intervention designed to avert future harm. Once protection is equated with the removal of capacity to act, the expansion of authority that accompanies guardianship or extended custodianship appears both natural and necessary.

However, alongside accounts that framed guardianship as an extension of care and protection, participants also expressed persistent unease about its entanglement with neglect and abuse. These concerns consistently returned to the same structural feature of guardianship: the transfer of extensive power to another person, coupled with fragile and uneven oversight. In these accounts, guardianship was understood to generate a risk environment of its own, one in which harm becomes more difficult to detect, name, and contest. Even where guardians are close relatives, participants emphasised that substitute authority is inherently vulnerable to misuse and error. As Serdar, a father, put it: “Even if it’s a brother, leaving someone in another person’s hands is a very big risk. People can be mistaken. Even very good people can be.”

These risks were seen to intensify further where guardianship intersects with financial interests. As discussed in Part 3, some participants emphasised that guardianship is sometimes pursued by families primarily to access benefits or allowances. In some of these accounts, guardianship emerged less as a protective arrangement than as a legal instrument through which financial advantage or control can be secured. As Onur, a lawyer put it bluntly: “They get the money, but the disabled person never sees it.”

Another lawyer, Ela similarly captured this recurring concern that financial incentives can increase vulnerability. For her, this risk becomes sharper in cases where parents are no longer alive, and guardianship shifts to other relatives or third parties. Highlighting the lack of oversight, Ela drew a stark contrast between cases involving no assets and those involving property:

> When the parents of an autistic child die without any property or assets, the state in Turkey does not simply leave that child on the street. One way or another, it places them somewhere. It places them in a private care institution. The conditions there, the expertise and so on, are all highly debatable, but at least the person is not completely abandoned […] But if there is property or assets left behind, and a guardian has been appointed, then there is absolutely no oversight over how that guardian cares for the person. Are they being tied to a radiator? Handed over to a carer at home and completely neglected? Are they experiencing psychological or physical violence or not? What condition are they in? Nothing. No one ever checks in or asks. In my view, these people are very often ruined because of their assets […] We do not even know where these people are.

Abuse was not confined to family settings. Professional participants described instances in which professional guardians treated guardianship as an income stream. Şeyda recounted cases of financial abuse, particularly in cases involving older people with dementia, where expenses were fabricated or inflated through false invoices, gradually draining bank accounts while maintaining a formal appearance of legality. Because records were “compliant” on paper and family members of the restricted person were often distant or absent, misuse frequently went undetected until after the person under guardianship had died.

Mechanisms for monitoring treatment, flagging harm, or holding guardians to account were described as uneven at best and, in many cases, effectively absent. While the law formally provides for oversight, these safeguards are applied inconsistently and, in many cases, deliberately relaxed “to avoid difficulty.” Onur offered a concrete illustration of how this operates in practice: whether an ordinary guardian is required by the courts to keep accounts may depend entirely on a judge’s approach. As he put it:

> The person placed under guardianship is sometimes not even aware of any of this […] If the judge has imposed an obligation to keep accounts, they ask for an annual or six-monthly statement. But if the judge hasn't imposed such an obligation… And I once spoke to a judge in Ankara who said, 'We usually don't require account-keeping, so as not to make things difficult.'

Participants also described cases where clear neglect did not prompt effective institutional response. Onur recounted a case involving basic care failures. He challenged the family directly and then raised the issue with the court:

> Well, for example, he said he hadn't been bathed for a year. He couldn't speak clearly […] but I was able to understand him. Afterwards, I told the family, 'Look, you're not bathing him. Isn't that a shame?' and so on. […] I told the judge as well, explained what was going on. He said, 'Mr Lawyer, am I supposed to deal with this?' Even though this is in fact part of the judge's responsibility.

As Onur noted, the judge did have the authority and responsibility to intervene, including the power to remove an inadequate guardian. Yet accounts like this suggest that the existence of formal powers does not translate into routine use, even where judges can act of their own motion.

Medical professionals echoed these concerns. Faruk described guardianship as a process that becomes uncertain once imposed: a legal status is created, but what happens afterwards is opaque:

> They place the person under guardianship, but what happens afterwards is unclear. Of course, they usually choose the guardian from among the person's closest relatives first, but is that person actually carrying out the role properly or not? Are they really meeting the person's needs? Are they taking their wishes, desires, and demands into account or not? Are they providing adequate material and emotional support? Unfortunately, these things do not function very well in Turkey. […] In those situations, we report the matter and request that the guardian be replaced, but it is a very slow and cumbersome system.

These accounts highlight a key problem: even when neglect or abuse is observed, reporting concerns to courts rarely leads to swift action, and legal response in such cases remains rare, slow, and patchy. When oversight and legal response fail in this way, as Onur put it, “people under guardianship are left alone with their fate.”

Negotiating Contradictions

Against this backdrop of permanent legal incapacity, concentrated authority and weak oversight, family members’ accounts also revealed deep ambivalence about the guardianship regime. Although institutional actors and many parents typically described guardianship as a necessary and protective response to intellectual disability, these instances instead pointed to the navigation of a grey zone shaped by contradictions, bureaucratic pressures, and anxieties about future risk.

Buket, for instance, framed the decision to place her son under guardianship as a compromise driven less by an assessment of her son’s abilities than by the demands of state bureaucracy:

> I actually took on Anıl’s guardianship, although I didn’t really need to. Why did I take it on? For example, I can’t get a passport for Anıl otherwise. […] That’s really why I did it, to be honest. Anıl didn’t really need guardianship, but in practice you sometimes run into bureaucratic obstacles, and guardianship helps to get around them.

From Buket’s perspective, the most painful consequence of guardianship was loss of voting rights. “Anıl loved voting,” she explained. “But now he can’t vote anymore. That’s the biggest problem with guardianship.”

Cemal expressed a similar ambivalence about guardianship and its consequences. Although his son was under guardianship at the time of the interview, he described sustained resistance throughout his son’s university education, despite repeated pressure. Guardianship, in his account, became unavoidable only when international travel was made contingent on it:

> Actually, we didn’t [put him under guardianship] throughout his university education. […] So, we resisted and didn’t take that step. It was directly imposed on us, like, ‘You must put him under guardianship; there could be issues you haven’t considered.’ But we didn’t do it. We believed that he could reach a level where he could manage himself. However, one day, the topic of traveling abroad came up. They made it a requirement for international travel, citing his autism diagnosis. So, we were forced to do it at that point.

A more explicit form of resistance appeared in Marin’s account. Like Cemal and Buket, Marin and her family were told that guardianship was required as part of their son Arsen’s passport application. Unlike many others, however, they were able to actively challenge the demand:

> It was four or five years ago during the passport application when we were asked if he has a guardian and we said, ‘No, Arsen doesn’t need anything like that.’ […] They didn’t know much but said, ‘This is an individual with autism, and it is a requirement for this.’ We responded, ‘No, it isn’t required. [...] Arsen is an individual who can travel alone. He votes, and my spouse is a doctor,’ and so on. And, in some way, we managed to get through that situation.

Marin did not reject guardianship outright, but she resisted its automatic and totalising application. Her account reflects a deliberate effort to delay restriction and preserve her son’s rights for as long as possible:

> Our aim, my spouse and I, was this: that he would become a grounded individual. We never wanted to take away his rights. […] But I’ve been trying to delay this process as much as possible. […] I’m with Arsen; I keep explaining things to him, giving examples. I observe him a bit for his sake. I don’t want to immediately take away his rights and put him in that position.

Crucially, in Marin’s account, vulnerability did not stem from her son’s impairment but from a social and institutional environment that pose risk. As she put it starkly, “If we have to take away Arsen’s rights because of those so-called clever types in society, then we will. But in reality, he doesn’t deserve this.”

Other families pointed to a system that oscillates between categorical restriction and categorical denial of support, producing contradictions across institutions that are difficult to reconcile in everyday life. Sibel described encountering this contradiction when she attempted to register a mobile phone line in her son Evren's name:

> The person […] told me that I also needed a custodianship document. I said, 'We've never taken any custodianship; we don't have anything like that.' Why should I take custodianship over a child whose general health insurance I pay for? It sounds completely absurd to me. Am I wrong?

Sibel was referring to Evren's health insurance premiums, which he must pay because he is unemployed and, according to his disability assessment, his impairment does not meet the threshold required to qualify for disability-related social security benefits. In this context, the requirement for custodianship seemed illogical to Sibel: while social security treats Evren like any other non-disabled, unemployed adult male citizen, his mental incapacity is assumed when it comes to managing a basic contractual relationship, such as registering a phone line.

Cemal articulated a closely related frustration, pointing to inconsistencies between legal and medical classifications. While the legal system assumes his son "cannot make his own decisions" and appoints a guardian, the social security system imposes a different threshold altogether, requiring him, in order to qualify for certain disability rights, to be classified as "heavily dependent on another person's care":

> The legal system grants guardianship because it assumes the person cannot make their own decisions. But at the same time, the healthcare system says that, in order for them to qualify for a disability pension after ten years, they must be considered heavily dependent on another person's care, and then refuses to recognise that. […] There is a contradiction. The legal system appoints a guardian, while the healthcare system says, no, this person is not severely disabled. In reality, both autistic people and their families become exhausted from constantly living with these contradictions and confusion.

These accounts show that the guardianship regime is not uncontested. Rather, it is marked by contradictions, tensions, and moments of resistance. In responding to these tensions, parents navigate and negotiate the guardianship regime, while often coming to accept it as necessary, or at least as the least harmful option available within a context of limited alternatives. That a less restrictive legal mechanism, i.e. legal consultancy (*yasal danışmanlık*), exists in Turkish law yet remained entirely absent from participants' accounts, and similarly unrecognised in institutional practice, points also to a significant gap between what the law formally permits and what disabled people and their families are actually offered in practice.

5. Rethinking Legal Capacity

The previous sections examined the legal and social dynamics shaping guardianship regime in Turkey. This final section turns to the interviews of intellectually disabled people to consider legal capacity from their perspective. Participants' accounts reveal a clear gap between the socio-legal constructions of intellectually disabled people as lacking capacity and their lived experience. While intellectually disabled people express and sustain legal capacity in everyday life through routines, relationships, and social interactions, these often remain unrecognised by formal legal frameworks and institutional practices. Participants' accounts also draw attention to the broader conditions that shape the practical enjoyment of legal capacity, including accessibility, access to information and communication, participation in decision-making, and the wider social and material conditions that make adult life possible.

Legal Capacity in Ordinary Life

Disabled participants' accounts challenge the assumption, embedded in law and practice, that intellectually disabled people lack legal capacity. What emerges instead is an understanding of legal capacity as something woven through everyday life in habits, preferences, relationships, and social interactions. It is often within this ordinary domain, largely invisible to formal institutions, that legal capacity can be enjoyed and recognised by those who know the person well.[7]

Disabled participants described decision-making as the ordinary, taken-for-granted substance of daily life. Their accounts were concrete and specific: planning, organising, refusing, choosing, and contributing. Özgür, for instance, described in detail how he prepared for a cruise, selecting outfits for different times of day:

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[7] See for similar findings in the England and Wales, Harding, R. and Taşcıoğlu, E. (2017) *Everyday Decisions Project Report: Supporting Legal Capacity through Care, Support and Empowerment*, Project Report. Birmingham Law School, Birmingham.

> For example, on the ship we dressed differently every afternoon, and in the evenings I wore smart outfits. I have a navy-blue shirt and light blue suit. I wore those. Elegant in the evenings. Stylish. My dad dressed up too. I dressed that way especially for my mum. I had two pairs of shoes as well. I packed them for the cruise so that I could dress smartly in the evenings.

Similarly, when Özgür attended a camp with his friends, he described taking on duties, managing his own space, and expressing clear preferences:

> I put the tablecloth on the table, put the water out, organised things. I took on a duty. Then I slept alone in the tent. I turned on my light. I turned on the torch my dad gave me. Alone. Then it was nice. They told me to eat *sucuk* at camp. I said no, I won't. They told me to eat ice cream. I said no, I won't.

Özgür also described himself as organised and self-directed, recounting how, a couple of days before our interview, he returned home alone, planning his next steps, and managing his environment:

> I'm organised. I stay at home on my own. I have internet. The other day I came from the seaside alone, without bothering anyone, just thinking in my own head. I came talking to myself: 'I'll wash my feet, then I'll turn on the TV.'

Other participants described similar daily activities: exercising, travelling, engaging in hobbies, and developing routines around clothing, food, and social life. Evren, for example, followed football teams Beşiktaş, Newcastle, Bayern Munich, and Feyenoord across different countries, tracking matches and results with sustained interest. These practices were central to how he shaped his life and understood himself as a person with preferences and social identities.

Legal capacity in everyday is also embedded in networks of support, familiarity, and trust. Family members' accounts illustrated how, over time, they learned to recognise and respond to the communication style, will and preferences of their disabled relative even when verbal communication is not available. As Ayten explained:

> Bora cannot express himself verbally. […] He mostly uses body language, and more recently, if he wants something, he taps his finger on the table, or taps more forcefully if he does not want it. Over the years, Bora has developed routines shaped around his preferences and choices.

Another mother, Deniz, described a similar process of attunement to her non-verbal son Cihan's ways of expressing his will and preferences:

> He doesn't express himself verbally, but he communicates through body language. He can ask for anything. I can almost always understand what he means. There are very few things I don't understand. For example, if he has a headache, he'll indicate that. […] He doesn't want something, he would tell that. For example, if I'm just going to give something to his grandmother, just stepping out for five or ten minutes, I'll say, 'Cihan, I'm going to your grandmother's to drop this off, do you want to come?' He'll go 'uh-huh' to say no. So I just go, drop it off quickly, and come back.

The relationship between Esin and her mother Sezin illustrated during their interview how this relational knowledge emerges and is put into use in ordinary life. Esin, a non-verbal disabled participant, took part in the study with her mother and through photographs she had taken of her daily routines, activities, and trips. She shared how she contributes to everyday domestic activities, setting and clearing the table, tidying the house, and taking responsibility for tasks. Her life is full and active: swimming, evening walks, browsing shops, listening to music. During the interview, we also had an exchange about a camping trip organised by the municipality that Esin was planning to go with her friends, and it was in this context that she communicated, through gestures, her wish to take a dress with her so she could dance in the evenings. This was an instance of decision-making: expressing wishes and preferences and having them recognised by the people and environments that enabled both their expression and realisation.

Participants also described their own capacity as variable, fluctuating across contexts, over time, and in response to environment and support. Periods of difficulty, linked to mental health, sensory overload, or environmental demands, were described as conditions to be anticipated and managed. Asu shared that she plans ahead to know what will happen the next day so that she can prepare mentally. Aslı explained how she anticipates periods of difficulty and organises her life around known patterns, including sustained contact with trusted mental health professionals and structuring her routines accordingly.

These accounts show how legal capacity can be supported through continuity, trust, and diverse forms of communication. At the same time, they underscore a persistent gap between lived experience and institutional recognition. Legal capacity that are present and enacted in everyday life often remain unrecognised in formal and institutional settings. The sections that follow examine the broader conditions that make the exercise of legal capacity possible, as well as the structures that continue to constrain and obstruct it.

Accessibility

Across the interviews, disabled participants described how the ability to make decisions, act on them, and have those decisions recognised by others was shaped, and often constrained, by the design of institutional and everyday environments. In this sense, accessibility functions as a precondition for entering, navigating, and participating in decision-making environments. In participants' accounts, accessibility importantly extended beyond physical access to include sensory conditions, navigability, and the social norms that structure interaction within those spaces. Where environments were inaccessible, engaging with systems became difficult, and the enjoyment of legal capacity was correspondingly restricted.

Healthcare encounters illustrated this particularly clearly. As a setting where decisions about treatment and care are routinely made, healthcare is a central site for the exercise of legal capacity. Yet participants consistently described healthcare settings as among the most inaccessible institutional environments they encountered. They identified a profound mismatch between institutional design and behavioural expectations on the one hand, and their sensory, embodied, and communicative realities on the other.

Hospitals were described as disorienting, noisy, and difficult to navigate, undermining anticipation, control, and interaction. Aslı explained how barriers began even before the clinical encounter itself:

> Hospitals are already terrifying places. Loud. I can’t find where I’m meant to go. If it’s a hospital I’ve never been to, it’s impossible. I need to arrive two hours early for the outpatient clinic… and because I can’t do those things, I’m terrible at this. Talking to doctors becomes very hard.

Even formal accommodations intended to improve accessibility do not necessarily resolve these barriers. In Aslı’s experience, disability priority queues often function in ways that increase waiting times rather than reduce them, prompting her to avoid them altogether: “There is supposedly a disability queue, but believe me, the disability queue comes later. […] I specifically say: ‘Please don’t give me the disability queue. I know the system says disabled, but please don’t.’ Because I don’t want to wait.”

Environmental inaccessibility was compounded by prejudice, distrust, and misrecognition by professionals. Aslı explained how the bodily markers of her disability and her medical history shaped how she was perceived and treated:

> Going to hospital is death for me. And I’m putting aside all the sensory stuff, all the things that are awful from an autism perspective. There is a terrible prejudice. I cannot get examined at all when I go. They say: one, I look different and act different. I ‘glitch’ there. Two, because my old prescriptions automatically show up, they treat me like this: ‘This person uses antipsychotics, so their mind isn’t sound and they’re making things up.’

These conditions transform healthcare encounters into sites of distress, loss of control, and withdrawal. Over time, such experiences discourage engagement with healthcare altogether. As Mine put it when discussing her own health needs: “I don’t go unless I’m dying.”

In moments of crisis, these dynamics intensify further. Nilgün, a mother, described how, during a severe breakdown, an ambulance refused to transport her son without police presence:

> Would you believe it, the 112 emergency services arrived. They said, “We can’t take him without the police, because he could harm us.” So then we had to wait for the police; they were called. I mean, can you imagine living through something like this? Your child is being taken into the ambulance accompanied by the police.

Information and Communication

Barriers to accessibility were closely intertwined with barriers to information and communication. Access to information and communication are fundamental conditions for understanding options, expressing one’s will and preferences, and participating in decision-making. However, the research shows that information is often produced and delivered in inaccessible formats, while non-verbal and alternative forms of communication remain insufficiently recognised and supported.

Disabled participants frequently described information provided by institutions as complex, difficult to understand, and inaccessible. Aslı expressed this as follows: “Doing anything official is very difficult in Turkey. The texts are very long, and the regulations are not at all helpful as a guide.” The difficulty described here does not stem from individual deficit, but from the way information is produced, organised, and presented. Although participants emphasised the importance of accessible information, easy-read and plain-language formats remain insufficiently known and rarely used in Turkey.

Participants also described how their support needs for communication were frequently neither recognised nor met. Mine illustrated this, describing how communication differences could themselves become a source of anxiety in healthcare encounters:

> Sometimes I talk too much and I talk without context. In a doctor relationship, giving too much information is not something the other side welcomes… […] From those communication ruptures, I can sometimes spiral into a collapse. I need someone next to me to stabilise the situation. Sometimes I can’t listen while I’m talking. Leaving the doctor without knowing what was said to me is a ridiculous thing.

The question of whether communication was recognised as valid emerged in participants’ accounts of pain and distress too. Aslı’s experience of back pain showed how pain can be treated as something requiring serious attention only when it is expressed through particular neurotypical emotional and bodily responses:

> For a very long time I had pain in my back and lower back, and it just wouldn’t go away. But none of the doctors took me seriously. […] I neither show how much pain I’m actually in, nor, for example, would I throw myself on the floor the way someone else might in my place. I’m not like that. […] The doctor says things to me like, ‘If something like that were really happening, you wouldn’t be able to sit like you do now.’ Yes, maybe I wouldn’t be able to, but right now I am sitting here and I’m still in pain. I may not be crying, but it’s very hard to explain that.

Our research shows also that, across both institutional and everyday life in Turkey, verbal speech is treated as the default and often the only legitimate form of expression. Alternative modes of communication, including writing, messaging, body language and assisted communication, were rarely recognised or accommodated, directly limiting individuals’ ability to express will and preferences in accessing services and exercising rights.

Aslı’s account of her use of alternative communication offered an especially stark illustration. In the interview, Aslı explained that her ability to communicate fluctuates depending on sensory overload, burnout, and context. Verbal speech is not always available to her: “My ability to speak just completely goes. For a while, I can’t speak at all. […] Especially when I’m burnt out, it completely goes.” Crucially, this did not indicate an absence of communication. Aslı relied on alternative modes of communication, including messaging, writing, and text-to-speech devices, to express preferences, distress, and decisions.

An emergency healthcare experience in which Aslı temporarily lost the ability to speak and was taken to hospital by ambulance revealed how such communication methods were rendered invalid within institutional settings. Although she was unable to speak and urgently needed to leave the hospital in order to recover, her discharge was made conditional on providing verbal consent: “They expected verbal consent from me to leave. But I can’t.”

Rather than developing an approach aimed at facilitating communication, emergency staff further intensified the pressure on Aslı to speak. Despite clear signs of distress, her silence was interpreted as non-cooperation, and she was repeatedly pressured into giving verbal responses, including through unwanted physical contact:

> They kept forcing me. They touched me by force. I’m actually very sensitive to touch. The more they did that, the more I couldn’t speak. None of them thought of a yes/no sign […] if someone there had simply given me a piece of paper with ‘yes’ and ‘no’ written on it, I’m sure it would have made things much easier for us.

Even when a friend supported her to communicate her wishes through writing on her phone, this was not accepted as valid. It was only when her psychiatrist, who was working at the same hospital and whose authority staff recognised, intervened that she was discharged. Aslı noted the stark contradiction between institutional claims and practice: “The funny part was that, at the entrance to the emergency department, there was this huge ‘we are aware of autism’ poster. Enormous, big enough to cover three or four people. And then there were experiences like these.”

These dynamics were not limited to healthcare. Sena’s account illustrated how differences in processing information and communication could escalate into criminalisation in public settings:

> I had many court cases. Because I couldn’t express myself. Someone touches me suddenly. I go into burnout, I go into meltdown. […] When someone like me, an autistic person, says ‘Why are you asking me for ID?’, if you take it personally as law enforcement… I was prosecuted for resisting [a law officer]. I have a sentence of 331 days. I had a horrific night. I was handcuffed behind my back, beaten by the police. Because it is not known.

Sena also described how the anticipation of being misread in public spaces produces ongoing anxiety: “In daily life I honestly can’t predict where a ball will come from, or how hard.”

Recognition, Support, and Participation

Building on issues of accessibility and communication, participation becomes the point at which legal capacity is either realised or denied in practice. Disabled participants emphasised that relatively modest adjustments could make a significant difference in their participation to decisions about their lives. Listening and allowing time for communication were described as transformative. Other practical measures, such as digitalised appointment systems, navigable hospital maps, quieter environments, functional priority systems, and alternative communication support, were valued precisely because they enabled participation rather than displacing the person from decision-making.

Aslı's experience with the sunflower lanyard scheme at Istanbul Airport offered a clear illustration. The scheme provides a discreet signal that enables contextualised assistance without requiring formal disclosure. Aslı described how this modest accommodation increased her independence without undermining her sense of control:

> It gives you so much independence […] No one comes and helps me specifically. But if I look even a little confused, someone immediately comes over and says, 'Look, you need to go this way,' and things like that. It was so good.

In the absence of accessible systems, many participants relied on the support and accompaniment of family members or friends to navigate everyday and institutional encounters. As Mine explained: "I'm usually only able to access healthcare with someone's support. Someone who can help me both socially and in processing information." While this informal support often functioned as a form of scaffolding that made access possible, it also introduced new forms of dependency and precarity. Mine described how her ability to manage everyday life depends on continuous assistance, which was becoming increasingly difficult to sustain: "My friends handled bureaucratic procedures. I've never gone to the doctor on my own. My parents still take me because otherwise there's no possibility of medical support, but now it's getting harder because they are in their 60s."

Disabled participants' accounts also showed that being physically present in decision-making settings, whether in healthcare, legal processes, or everyday interactions, does not necessarily mean being involved. Attempting to access services or rights through accompaniment can produce a different form of exclusion. Rather than facilitating participation, the presence of others sometimes leads to the displacement of the disabled person. As Aslı explained about hospital visits: "When I go with my family, then they just speak to my mother all the time. They don't speak to me at all. Even if I'm only standing there, they still don't speak to me."

This dynamic, in which the presence of a supporter or family member redirects the communication away from the disabled person entirely, was part of a broader pattern of non-recognition in institutional encounters. Disabled participants described being physically present during discussions about their own care or circumstances yet not recognised as the relevant interlocutor.

In such situations, presence did not translate into participation: conversations and decisions were made about them, but without their meaningful involvement.

Participation becomes possible where individuals are recognised as relevant interlocutors whose views are sought, heard, and acted upon. Disabled participants described such encounters as moments of recognition: instances in which they were treated as legitimate knowers of their own experiences. Aslı highlighted the importance of having her experience and knowledge taken seriously. In encounters where doctors dismissed her account by telling “I’ve seen countless patients, are you teaching me?”, she felt disempowered. By contrast, when doctors were willing to revisit and verify what she said, this created space for recognition and enabled her participation in decisions about her own care:

> But with Dr Pelin, for example, it’s not like that. For instance, I thought I might have dyspraxia, but I didn’t really a diagnosis of it. […] She said, ‘I don’t know, I’ve never looked into it, let me check.’ Then in the next session she said, ‘Yes, you really do have this.’ We went through things like this. And that is such a huge blessing.

Orhan’s account also showed how participation becomes possible through relationships of continuity, trust, and recognition. He explained that his participation in decisions about treatment only became possible once care shifted away from constantly changing doctors towards a stable relationship in which trust and recognition could develop:

> After constantly seeing different doctors who didn’t know me and treated me as if they were meeting me for the first time each time, having a consistent doctor and a stable course of treatment had a very positive effect. After I met Dr Hande, a more understanding doctor–patient relationship developed. There were certain medications […] With Dr Hande, we were making those decisions together and implementing them mutually.

Adil, a lawyer’s account similarly highlighted the importance of relationships and relational knowledge in enabling participation. Adil shared a sexual violence case involving an intellectually disabled woman in which meaningful participation in the legal process became possible through appropriate support. Although she was initially hesitant to speak in court, her participation was enabled through sustained engagement: “Empathy, one-to-one communication, really trying to communicate… We approached her as a subject, as a person. We treated her like our other clients." With the involvement of her sister and expert support, she was able to give evidence, and the defendants were convicted.

Adil described enabling her testimony as "a somewhat risky decision," yet maintained that it was the correct one. Rather than treating risk as a ground for exclusion, participation was made possible by recognising her as an active subject within the process, adapting communication, and working together with trusted supporters. Reflecting on this experience, he emphasised how it gave concrete meaning to Article 12 of the CRPD and to the support paradigm in the following words:

> In the end, I can see that intellectually disabled people, or even people with more severe intellectual impairments, can very comfortably express themselves as individuals, as persons, with appropriate support and assistance, and that their will and preferences can be brought out very clearly. When I think back to that day, to 20, 24 years ago, I can see how clearly this could be made possible. If you hadn't asked this question, those memories would probably have remained buried somewhere in my subconscious. But now, when I remember it, I can understand much more concretely what Article 12 of the United Nations Convention on the Rights of Persons with Disabilities is really trying to say.

Conditions for Living an Adult Life

Our research shows that the enjoyment of legal capacity depends not only on accessible environments, recognised communication, and supported participation in decisions. It also depends on the structural arrangements through which disabled people are recognised and supported as individuals who can shape their own futures. While legal frameworks often position disabled people as perpetual children or dependants, participants' accounts emphasise the importance of inhabiting an adult life in practice: through access to employment, opportunities for independent living, and participation in community life.

Transition to Adulthood and Pathways to Employment

Across interviews, the transition to adulthood emerged as a critical point at which few formal systems of support that exist fall away, leaving disabled people without clear routes into employment, independent living, or wider social and cultural participation. Nilgün, a mother, described how state support largely disappears after a certain age: “The real problem begins after the age of 20. Once they graduate from those special education practice schools, they are left within four walls with their family, with their mother, and, if present, their father.”

This reflects the way social care support for adult disabled people in Turkey is largely organised around family-based care arrangements. The disability allowance (*engelli aylığı*) and disability care allowance (*engelli bakım aylığı*) are both primarily allocated on the basis of disability percentage — requiring an impairment assessment above 40% — alongside the income and resources of the household rather than the disabled person as an independent rights-holder. As a result, these schemes reinforce rigid distinctions between disabled people deemed to require support and those considered not to, while remaining structured around assumptions of familial care and dependency, with little provision for independent living or community participation.

The other form of state support available for intellectually disabled adults is the special education benefit, under which eligible disabled people — with an impairment assessment above 20% — can receive a monthly allowance to attend special education and rehabilitation centres. Attendance at these centres remained common among our intellectually disabled participants and the disabled children of family members long after the completion of formal schooling. These centres were valued by families as important sources of respite from care responsibilities and as among the few spaces in which disabled people could participate socially outside the family. Disabled participants who attended similarly valued them for the opportunities for socialisation they offered, and friendships formed there often extended into everyday life.

This provision, however, is narrow in scope and conditional in reach: it extends state support beyond the family, but only through an educational model, positioning disabled adults less as individuals entitled to shape their own lives than as learners in need of continued training and supervision. Where education functions as a holding structure rather than a purposeful pathway, however, it also tends to be organised around managing perceived deficits rather than building on strengths, interests, or aspirations.

During our interview with Özgür, his father Özer described the logic driving continued attendance: “We keep continuing with education, because repetition is very important for [intellectually disabled individuals], so they don’t forget. They might forget how to read and write otherwise. That’s why the education continues.” Cemal, a father, described how his son’s university education was shaped less by his abilities or preferences than by an effort to address what he was seen as lacking: “While everyone else plans around the area where a person is most capable, talented, or skilled, […] we chose [that field] because he was weak in it […] in order to develop his abilities.”

The continuing centrality of education reflected its role as the primary structured activity available to intellectually disabled adults. Ongoing participation in education often functioned less as a chosen pathway than as a response to the absence of alternatives, i.e. the lack of post-school support, employment pathways, or community-based programmes. This was evident in Saniye’s description of why they decided to keep her son in formal education for an additional year after graduation from high school rather than pursue further education or employment:

> Now we’ve actually finished there and he’s graduated. […] The teachers said, and I honestly thought the same. I even suggested it myself: if he just stays at home, what will he do? Sit, sit, sit all day. At least when he goes [to the school], he goes in and out, sees his friends, spends time. It’s good for him. […] So we decided to have him repeat the year. He’ll go there for another year, and after that… he’ll just be at home. Unless some kind of job comes up.

Disabled participants also shared that transitions from school to employment were uncertain and inadequately supported. As Sena explained, existing educational policies “do not work towards employment for inclusion students.” Access to employment is also shaped by standardised systems that reproduce exclusion and fail to accommodate different needs. Sena, for example, criticised the Public Personnel Selection Examination for Disabled Candidates[8] for assessing different disability groups according to the same criteria:

> They put all disability groups into the same content. The same questions are asked to all disability groups. For example, I'm terrible with idioms and proverbs. I don't understand figurative meanings. Questions about errors in expression are torture for me.

The gap between schooling and adulthood was reflected in employment outcomes of our participants. Only a small number of disabled participants were in paid employment, and employment was far rarer among the disabled children of the family members we interviewed.

Despite these barriers, employment emerged in our interviews as a critical site for recognition, contribution, and existing as an adult within economic and social life. For example, Orhan emphasised that work gave him both a sense of agency and fulfilment: "Working life is really helping my long-delayed wishes come true one by one." Murat excitedly shared his plans to work together with his older brother:

> Murat: My older brother is going to be a pharmacist, and I'll work with him. I'll make tea. I'll make coffee. I'll do everything.
>
> ET: Will you deal with customers too?
>
> Murat: Of course I will. And I have a younger brother, Aytaç. He's started working too.

Cemal similarly emphasised the significance of employment for his son while expressing his frustration at seeing him complete higher education yet remain excluded from work: "After university, he needed employment so that he could enter working life, use his time meaningfully, and truly feel like an individual, like a citizen. Unfortunately, we were not able to provide that."

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[8] A centralised state examination in Turkey used for the recruitment of disabled individuals into public sector employment.

Where opportunities for work did exist, they were often fragile, and dependent on informal arrangements. Sibel described how working had transformed Evren's sense of himself, and how quickly that could be taken away in the absence of stable institutional support for access to work:

> If Evren is going to work at the canteen, the night before he says, 'Mum, I'm going to work at the canteen.' His father and I go there, have some tea, and even leave a tip. That really pleases Evren and the kids he works with. That's how it was. But what happened then? They shut the canteen down. It's just empty there now.

Although rare, inclusive practices did emerge in some workplaces. These practices largely depended on personal initiative rather than institutional frameworks, yet their impact on disabled participants' ability to participate in working life was considerable. Aslı described the impact of a "workbuddy" system that, although originally intended to last only a short time, continued for several months: "That guy, without even realising it, basically saved my life. Normally, apparently, being a workbuddy lasts a week or ten days, but he did it for me for three months. I asked him everything. And he answered everything." Aslı also explained how small communication adjustments, such as using written chat during meetings or receiving written notes afterwards, made active participation in working life possible. These changes benefited not only Aslı, but also the wider team by creating clearer workflow and communication.

Independent Living

Independent living emerged as a key aspiration for disabled participants, but one that was significantly constrained in practice. Participants consistently framed independence not as the absence of assistance, but as something that depends on the availability of reliable and appropriate support — support that remained unavailable through publicly funded services. Many participants relied instead on informal, unpaid, and often gendered networks of support. Family members, most often mothers, played a central role in sustaining everyday life, from navigating bureaucratic processes to ensuring that basic daily needs were met. While essential, these arrangements were uneven, unsustainable, and often reproduced forms of dependency that sat uneasily with the aspiration to independent living.

Mine's account captured how the invisibility of such informal forms of support can become apparent only when they disappear. Reflecting on a period in which her support networks were disrupted and exposed the extent to which her everyday life had depended on them, she shared: “It turned out I actually had quite strong support systems. Once they disappeared, I started making serious mistakes.” Aslı’s account further illustrated how managing daily life remains difficult without support: “I think about this a lot. I will probably never live completely on my own. I’ll never be able to do things in a fully independent way, because there are many things I can’t do.”

Aslı went on to describe the everyday implications of this in concrete terms:

> I never remember to drink water, I never remember to eat. Unless someone tells me to. […] I mean, okay, you can pick up water and drink it, but if you tell me to cook, there’s a chance I’ll burn the house down. I might make the food and then not eat it. […] In one sense I could live alone, but my quality of life would drop dramatically and, for example, after a month and a half or two months, I’d probably end up collapsing. I’ve actually fainted before because there was nobody at home and I wasn’t drinking water.

What emerged from this account was a call for structured forms of assistance that would make independence feasible in practice. Aslı made this explicit when describing the kind of arrangement she would need:

> I don’t know in which country it is. But, you know, if you want, people come to your home for maybe two and a half days or something, or they stay with you all the time. The state provides it. If there were something like that in Turkey, I would move into my own place immediately, the very same day. Because I really want that. But I can’t do it as things are now, there’s absolutely no possibility. Still, I would want something like that so much.

Independent living was discussed also in relation to the future. Both disabled participants and families were often acutely aware that the informal support provided through family cannot be sustained indefinitely. The question of how disabled people might live, work, and be supported as adults once parents are no longer able to care for them gave particular urgency to demands for structured support systems. In this sense, support for independent living, like support for employment, is necessary not only to enable independence in the present. It is also what makes adult life beyond the family possible, and a viable future imaginable.

Community Participation and Self-Advocacy

The accounts examined in this section point to a further condition for the practical enjoyment of legal capacity: the ability to participate in community life and to be represented within the structures and processes that shape it. Participants described friendships, peer communities, shared activities, and collective forms of organising as central sources of recognition, belonging, and participation. Yet opportunities for community life were often concentrated within family and educational settings, rather than being supported across wider community contexts.

The relationship between Esin and her mother Sezin offered a striking example of how their shared life could also come to define the boundaries of Esin's social world. Sezin explained that she had asked the teachers at Esin's special education centre to approach her not as authority figures, but as friends: "I said, when she comes, be like friends with Esin. Don't be an authority over her, don't be a teacher or an older sister. Be a friend." Drinking tea, baking cakes, and spending time together with her teachers had become a clear source of happiness for Esin. Yet it also pointed to a structural limitation. In the absence of opportunities where Esin could independently form friendships, her relationships with teachers were being reshaped to fill the gap. As Sezin put it: "Because she doesn't have friends. The average age of her friends is 70. My friends are also my daughter's friends." In this context, Esin's plans to go on a camp trip took on a particular significance, as they pointed to the possibility of a space in which she could form relationships with others closer to her own age and identity, beyond the social world she shared with her mother.

For intellectually disabled participants who had found peer communities of their own, the difference was marked. Those who had connected with others like them emphasised the mutual recognition and understanding these relationships made possible. Aslı explained:

> Having autistic friends is such a wonderful thing. It's like there's someone in front of you who speaks the same way as you do. For example, Anıl and I definitely don't have the same interests at all, but we can talk so comfortably, and we have such a lovely relationship. Or, for example, İpek, Mine. I'm in contact with all of them. They taught me very valuable things. That support taught me so much.

These relationships offered something that other settings failed to provide: recognition on one's own terms, and communication or behaviour that did not need to be constantly justified. Yet Aslı also acknowledged the ongoing difficulty of limited social network: “Loneliness is still a big problem for me, by the way. I don’t have many friends right now, but I’d genuinely like to have a few more. Because sometimes you feel alone.”

Beyond peer relationships, participation in civic and collective life provides a key avenue for recognition, belonging and contribution. Arsen’s participation in voting, as described by his mother Marin, highlighted how engagement in civic processes can be both meaningful and affirming: “He loves [voting] […] He even says, ‘Mum, I voted for CHP. Did I do well?’” In the absence of formal employment, Semih had built a life of sustained civic engagement on his own terms. His extensive engagement in volunteering, cultural production, and local governance illustrated a life organised around commitments and public participation: ““Because of my particular circumstances, I cannot work in paid employment, so I work in voluntary organisations instead. I serve as a member of disability councils within city councils.”

Participants’ accounts also offer glimpses of what a different relationship to advocacy and self-representation can look like. Mine described their self-advocacy group as something that actively sustained her capacity to function day to day:

> I like organising, I’ve come to understand. I felt its absence as a gap. […] Organising and being part of something is what replenishes my spoons. When I’m just at home trying to manage things, I find I can’t move.

These accounts show that peer networks, community life and advocacy provide forms of recognition, participation and support that other settings rarely generate or acknowledge. In that sense, what they suggest is that the empowerment and organisation of intellectually disabled people on their own terms, in their own communities, and through their own forms of participation is not a peripheral concern. The realisation of legal capacity depends also on the presence and participation of intellectually disabled people in the spaces where their rights, including right to legal capacity are defined, debated, and enacted.

Recommendations

The findings of this project demonstrate that realising the right to legal capacity in practice requires more than formal legal reform. It also depends on transforming the institutional, social, and political conditions that shape disabled people's lives.

In light of these findings, we make the following recommendations:

1. Reform the legal framework on legal capacity (CRPD Article 12)

The legal framework should be aligned with Article 12 of the CRPD. This requires recognising legal capacity as universal and establishing systems that ensure individuals are able to enjoy their legal capacity with appropriate support and safeguards.

2. Shift public attitudes (CRPD Article 8)

Public perceptions and attitudes that view intellectually disabled individuals as dependent or solely in need of protection must be transformed to recognise them as adults with equal rights.

3. Ensure accessibility (CRPD Article 9)

Public services should be made accessible, including for sensory and cognitive diversity, so that individuals can navigate systems and participate in decisions affecting their lives.

4. Ensure accessible information and communication (CRPD Article 21)

Information should be provided in formats that individuals can understand, process, and use, including easy-read and alternative formats. Alternative and augmentative forms of communication should be recognised and supported across institutional settings.

5. Strengthen professional training and practice (CRPD Article 13)

Professional training should be strengthened across legal, medical, and public service sectors to ensure alignment with the CRPD and supported decision-making approaches.

6. Strengthen pathways to employment and independent living (CRPD Articles 27 and 19)

Policy should focus on developing structured transitions from education into employment and publicly funded personal assistance schemes to support independent living and reduce reliance on family-based care.

7. Support community participation and self-advocacy (CRPD Article 29)

Opportunities for community engagement should be strengthened to enable intellectually disabled people to participate fully in social and civic life. This requires sustained funding and support for organisations led by intellectually disabled people, as well as ensuring their meaningful involvement in the design, implementation and evaluation of laws and policies that affect them.