



The Right to make decisions



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1.

Making decisions

The United Nations Convention on the Rights of Persons with Disabilities says that countries must respect everyone's right to make decisions, including people with disabilities.

The right to make decisions is very important to access many other rights:

- the right to choose where and who you live with
- the right to vote and be elected
- to make healthcare decisions
- the right to marry and have a family¹
- to have a bank account
- control your own money and property²

2.

What does it mean to have your legal capacity denied?

Some laws and policies prevent people with disabilities making their own decisions they have many names across countries (curatorship/ but they are known as

¹ Committee on the Rights of Persons with Disabilities, 'Article 12: Equal recognition before the law' (2014), 8.

² Inclusion Europe, 'Easy-to-Read Definitions: Legal Capacity' (please see [here](#))

guardianship that can have different level of restrictions. They may prevent someone from making decisions for themselves and appoint someone else to make decisions for them, such as:

1. Personal decisions, e.g. *to choose where they live and with who they live.*
2. Medical decisions, e.g. *to make decisions about healthcare*
3. Financial decisions, e.g. *to control their property*

Guardianship and substituted decision-making can never be a good system regardless of the degree of the guardianship and the level of support needs.

3.

Supported Decision-Making

Supported decision-making is support that helps someone to make their own decisions. There are many types of supported decision-making, such as:

- **Supported decision-making agreements:** They are agreements that do not need a judge to choose someone to help you make decisions.
- **Co-decision-making:** They are when you choose someone who will make decisions with you. To be a real form of support, people must be able to choose voluntarily who helps them making decisions and to change their minds whenever they want.
- **Peer Support:** People provide knowledge, experience, emotional, social or practical help to each other.³
- **Independent Advocates:** They support a person to make decisions and talk to all the other people involved.

³ Look at Inclusion Europe project [TOPSIDE](#) on peer support.

- **Advance Directives:** When you write down what you want to happen in the future so others can see what your choices are. In many countries the law says other people are not always obliged to follow your choices.”⁴



Legal capacity is essential because it means that the law and other people must respect your decisions. People with intellectual disabilities are too often denied their legal capacity and are subjected to substituted decision-making regimes.⁵ Inclusion Europe calls for the recognition of universal legal capacity in Europe to ensure that people with intellectual disabilities are fully included in all aspects of life and have the same rights in practice as everyone else.

“Imagine that you fall in love with another person. And the other person falls in love with you. You become a couple. And then you want to get married. But it is not that easy.

⁴ General Assembly, ‘Report of the Special Rapporteur on the rights of persons with disabilities’ A/HRC/37/56 (12 December 2017), 7 and Easy-to-Read version, at 21.

⁵ Committee on the Rights of Persons with Disabilities, “General Comment No. 1” (19 May 2014) CRPD/C/GC/1, 2.

You need to come before a judge. The judge can decide if you can get married. And he asks you: "What is love?" This is a very difficult question.

Many people have written about it. But they have not found the answer. Why do you need to find an answer only because you want to get married?" Senada Halilčević ·

4.

What is Legal Capacity?

"Legal capacity is the ability to hold rights and duties (legal standing) and exercise those rights and duties (legal agency)."⁶

Legal capacity is the right to exercise legal rights and to make decisions that can be legally binding.⁷ It is the right to make decisions and to have those decisions respected by the law and other people. It is also the right to make mistakes, to learn from it and flourish as everyone else.

All persons have the right to recognition of their legal capacity.⁸ The United Nations Convention on the Rights of Persons with Disabilities reaffirmed that regardless of the need of support to exercise their legal capacity, people should not be denied the right to get support in decision-making.⁹

⁶ See n (4), 3.

⁷ General Assembly, Report of the Special Rapporteur on the Rights of Persons with Disabilities A/HRC/37/56 (12 December 2017) 14.

⁸ See n (4), 3.

⁹ See n (4), 7.

Recognition of legal capacity is important to access many other rights, including:

- Managing, owning or inheriting property¹⁰
- Accessing to financial resources, including loans and mortgages¹¹
- Having a birth certificate and passport
- Making medical decisions¹²
- Living independently¹³
- Choosing where or with whom to live¹⁴
- Getting married and found a family¹⁵
- Accessing to justice¹⁶
- Voting or standing for elections¹⁷

There is never a justification for denying or restricting the legal capacity of an individual, “[a]t all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.”¹⁸

Where an individual’s choice cannot be ascertained, the decision must be based on the best interpretation of the individual’s will and preference not on the best interest principle, as indicated through prior manifested preference or advanced directive etc.¹⁹

¹⁰ See n (4), 7.

¹¹ See n (4) 3.

¹² See n (4) 3.

¹³ See n (4), 9 and 11.

¹⁴ See n (4), 12.

¹⁵ See n (4), 8.

¹⁶ See n (4), 10.

¹⁷ See n (4), 12.

¹⁸ See n (4), 5.

¹⁹ Ibid 31.

5.

What does it mean to have your legal capacity denied?

People with intellectual disabilities are too often denied their legal capacity and subjected to substituted decision-making.²⁰ It means they cannot make decisions by themselves but that someone else is making decisions for them. Women with disabilities, people with complex support needs and older persons with disabilities are also particularly at risk of being subjected to substituted decision-making.²¹

“Imagine if someone else was making decisions for you. They could decide to take you away, lock you up, not listen to you, give you medication, block you from doing your work and living your life with your body and mind the way they are”²²

There are many different laws and practices that provide for substituted decision-making, including;

1. Plenary guardianship
2. Judicial interdiction
3. Partial guardianship²³

Even where there is no formal or legal denial of a persons’ legal capacity there may still be informal substituted decision-making.²⁴

Denial or restrictions on the legal capacity of an individual can have a profound impact on their life. People who are denied their right to legal capacity may be prevented from accessing many of their other rights, and as a result may be for example:

²⁰ See n (4), 2.

²¹ Ibid 17 and 18.

²² International Disability Caucus: Advocacy paper during Ad Hoc Committee on a Comprehensive and Integral International Convention on and Promotion of the Rights and Dignity of Persons with Disabilities, Nothing about Us without Us, 31 January 2006.

²³ See n (4), 6.

²⁴ See n (3) 16.

- **Assessed unable to vote and stand for election** ²⁵
 - ➔ *"I am under comprehensive guardianship. [...] Because of this I cannot vote and we cannot get married either. I am not the only one with these problems, there are many of us. I cannot sign an employment contract; I cannot work so I have many such disadvantages."* (Man with intellectual disabilities, 53, Hungary)²⁶

- **Denied the Right to assembly**
 - ➔ The denial of legal capacity also has an impact on collective rights. People will be prevented to participate through an organisation as it will not have legal standing. Access to funding will be compromised due to the impossibility for people to open a bank account.²⁷

- **Denied access to justice**
 - ➔ *Legal capacity and ECHR article 5 on right to liberty "In the Kędzior case, for example, the ECtHR noted that the law does not prescribe periodic reviews of the need for detention when the placement is considered voluntary, and the lack of legal capacity prevented the individual from initiating any judicial remedy against his detention."*²⁸

- **Prevented from choosing where and with whom to live**
 - ➔ *One woman living in a protected home in Bulgaria wanted to live in her grandmother's house, but her uncle, who is on her guardianship council, disagreed: "He told me that he is afraid I would not be able to live alone in the house as it is not safe. He thinks there is a chance that I might be attacked by criminals as the house is located in the suburbs of a village."*²⁹ (Woman with intellectual disabilities, 44, Bulgaria)³⁰

²⁵ See n (4), 8.

²⁶ FRA report on legal capacity, p.45

²⁷ Inclusion Europe submission on CRPD General Comment n°7

²⁸ FRA report legal capacity, 2013, p19

²⁹ FRA report on legal capacity, 2013, p.47

³⁰ FRA report on legal capacity, 2013, p.47

- ➔ *One woman participating in a project led by Inclusion Europe left an institution and still strongly felt the lack of control over her life: “My biggest fear is that I will be put back into an institution”³¹*
- ➔ *“Nina lived on her own for quite a while. Then suddenly five people were added to the house. Nobody looked at whether this would be a match or not, they were just suddenly there. Nina became scared and withdrawn. Nobody tried to find out what she wanted. She was not allowed to have a good time with the others, not even with the one man she did get on with. The staff wanted to control everything.” Nina’s mother, aged 38³²*

- **Refused the right to marry and found a family**

People with intellectual disabilities are often demanded more than others to be “allowed” to express their love, which can lead to grotesque situations: an example reported by Senada Halilčević, Inclusion Europe Vice-President : In Croatia, a judge had been confronted with the “task” to decide if a couple with intellectual disabilities had the “capacity to get married”. He chose to ask them a question that no one can give a definitive answer to: “What is love?”

- **Declared unable consent to medical treatment**

- ➔ *“Respondents with intellectual disabilities in Romania highlighted that it was difficult to challenge family pressure because parents often acted as the contact point with medical professionals: Unfortunately [the doctor] doesn’t discuss [my treatment] with me, but with my mother.” (Man with intellectual disabilities, 30, Romania)³³*
- ➔ *“My mother didn’t tell me about the treatment’s side effects. [...] Unfortunately, I felt them by myself. [T]he medicine I was taking, it made me feel intoxicated, dizzy.” (Man with intellectual disabilities, 30, Romania)³⁴*

³¹ VAW project, more information [here](#).

³² (n32)

³³ FRA report on legal capacity, 2013, p.49

³⁴ FRA report on legal capacity, 2013, p.51

• Make daily life decisions

- ➔ “One woman living in a residential home in the United Kingdom described how severely curtailed were her opportunities for making even small decisions such as what time to get up and what to eat: *‘My mum is my guardian and I can’t say ‘no’ to her. If she wants me she can phone up the house. And the house phones her. Everything is controlled by her. And I can’t breathe. Because she’s there – in my face. In this. In that. And you know she’s everywhere. [...] I know she’s my mum but I’ve tried to move away from her slowly but it’s not working.’* (Woman with intellectual disabilities, 27, United Kingdom)³⁵
- ➔ *“I get a small disability allowance. [...] My mother takes this money.”* (Man with intellectual disabilities, 21, Romania)³⁶
- ➔ *“I was placed in care at 11 months of age. As a child I was always moved around. Like a lost parcel in the postal services. Every time I reached a certain age, I had to move again. I just wanted a home. Somewhere I felt safe.”* Mary, aged 47 (Life after violence)

The Committee on the Rights of Persons with Disabilities has expressly stated that a disability or an impairment can never be a reason for denying an individual their right to legal capacity.³⁷

Restrictions and limitations on legal capacity don’t just deny the rights of people with disabilities, they also “perpetuate discrimination and exclusion against persons with disabilities and pave the way to different forms of abuse, corruption, exploitation, coercion, exploitation, coercion and institutionalisation.”³⁸

³⁵ FRA report on legal capacity, 2013, p.44

³⁶ FRA report on legal capacity, 2013, p.45

³⁷ See n (4), 3.

³⁸ General Assembly, Report of the Special Rapporteur on the Rights of Persons with Disabilities A/HRC/37/56 (12 December 2017) 16.

6.

Supported Decision-Making

“Systems of supported decision-making should not over regulate the lives of persons with disabilities.”³⁹

Education plays a key role in supporting people to improve their ability to make decision and get more autonomy and acquiring independent living skills. The impossibility for a child to attend regular schools and in some cases, to grow in an institution as opposed to a family environment prevent his/her from developing decision making skills.

State parties cannot just remove substituted decision-making, they must replace it with supported decision-making options.⁴⁰

Supported decision-making is the support provided for individuals to make their own decisions, there are many types of supported decision-making mechanisms. Supported decision-making must be available to everyone.⁴¹ A person must be able to choose the form and duration of support, and be able to change the support or end it at any time.⁴²

Supported decision-making includes many laws and practices, such as:

1. Supported decision-making agreements⁴³
2. Co-decision-making agreements⁴⁴
3. Independent advocacy⁴⁵
4. Peer support⁴⁶
5. *Advance planning*: which enables a person to “state their will and preference which should be followed at a time when they may not be in

³⁹ See n (4),7.

⁴⁰ See n (4), 6.

⁴¹ See n (4), 7.

⁴² See n (4), 7.

⁴³ See n (3), 7 and Easy-to-Read version, at 21.

⁴⁴ See n (3), 7 and Easy-to-Read version, at 21.

⁴⁵ See n (3), 7 and Easy-to-Read version, at 21.

⁴⁶ See n (3), 7 and Easy-to-Read version, at 21.

a position to communicate their wishes to others.”⁴⁷ However, advance planning should not come into effect because someone is deemed “incapacitated.”⁴⁸

The level of support needed should not prevent an individual from receiving the support necessary to make decisions, everyone should have options to choose the support they would like for decision-making.⁴⁹

Supported decision-making should support people to make their own decisions, and people with intellectual disabilities must have the same right to make mistakes or be wrong as everyone else.⁵⁰

Sometimes, member states can present so-called “Supported decision-making” that are not truly respectful of one’s will and preferences. Therefore it is important to be sure people who needs support can

- *choose the type of support they want if they want support*
- *choose when they want the support/when they want it to stop.*

*As the Special Rapporteur stressed: Support for supported decision-making must always be based on the will and preference, or where it is impracticable to obtain the will and preference, the best interpretation of the will and preference of the individual. Supported decision-making must never occur on the basis of best interest.*⁵¹

⁴⁷ See n (4), 5.

⁴⁸ See n (4), 5.

⁴⁹ See n (4), 7.

⁵⁰ See n (4), 5.

⁵¹ See n (4), 7. See also Inclusion Europe paper on legal capacity.

7.

Safeguards for legal capacity

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In order for supported decision-making to be respectful, adequate and appropriate, some safeguards need to be put in place. Safeguards can be seen as individualised arrangements in the process of identifying ones’ own will and preferences, but also a set of measures to prevent supporters overstepping their duties or even damaging the person they support, to guarantee that the person’s rights, will and preferences are respected.

General Comment n. 1 provides for eight crucial features of safeguards⁵⁴:

- Appropriate and effective to prevent abuse, by both the supporters and third parties.
- Respectful of the right of the person. Safeguards cannot in any case limit any right laid out in the CRPD, such as the right to vote (art. 29), the right to marry and found

⁵² See n (4), 5.

⁵³ See n (4), 7. See also Inclusion Europe paper on legal capacity.

⁵⁴ See CRPD Committee, General Comment n°1, § 20.

a family (art. 23), the right to choose where to live (art. 19), access to justice (art. 13).

- Respectful of the will and preferences of the person, replacing the “best interest” principle.

The notion of “best interpretation of will and preferences” allows for decisions when will and preferences cannot be determined with certainty. It is also necessary to set up standards for situations in which expressed will and preferences would lead to serious harm, as well as in cases of conflicting will and preferences.

- Free of conflict of interest and undue influence, that might undermine the relationship between the supporter and the supported person and this latter’s freedom of choice.
- Proportional and tailored to the person’s circumstances. The person supported should always be involved in the assessment and re-assessments of the kind of support needed.
- In place for the shortest time possible. Capacity should be understood as a dynamic notion taking into account also potential future changes. In any case, as soon as a specific measure becomes unnecessary or unwanted by the supported person, it needs to be removed.
- Subject to regular review by a competent, independent and impartial authority or judicial body. The body should be made up of experts who have competence in human rights and other legal requirements, independent from other bodies and impartial with respect to other interested parties.
- Proportional to the degree to which such measures affect the person’s rights and interests, in order for the person to not receive too little or too much of the support.

Inclusion Europe fully supports the transition from substituted decision-making to supported decision-making, which is a right that must be recognized in national law according to the correct implementation of CRPD and the relevant jurisprudence. Good-quality information around supported decision-making schemes and how to access them should be made accessible to people with disabilities, their families and other relevant stakeholders, including national registries of supporters or other forms of legitimation and monitoring.

Video/ articles on supported decision making

www.right-to-decide.eu

Fundamental Rights Agency (FRA) [report](#) on legal capacity

Mental Health Europe (MHE) [report](#) on exclusion

Inclusion Europe [position paper](#) on safeguards for legal capacity

Inclusion Europe [article](#) on launching www.right-to-decide.eu

Inclusion Europe [article](#) on legal capacity

Inclusion Europe [article](#) on “best interest” principle

Inclusion Europe [article](#) on guardianship

[Positive testimony](#) on regaining the right to vote