



# European Human Rights Report

Issue 8 – 2024

**Legal capacity: Personal choice and control**



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# Contents

<b>This human rights report is dedicated to Jolijn Santegoed and Sir Robert Martin</b>	<b>6</b>
In memory of Jolijn Santegoeds	6
In memory of Sir Robert Martin	7
<b>Glossary</b>	<b>8</b>
<b>Forewords for the EDF human rights report on legal capacity</b>	<b>13</b>
<b>Executive summary</b>	<b>20</b>
<b>Introduction</b>	<b>22</b>
Methodology	23
<b>CRPD update in Europe</b>	<b>24</b>
Ratification of the CRPD	25
Submission of initial report to the CRPD Committee	26
Ratification of the optional protocol to the CRPD	27
<b>What is legal capacity?</b>	<b>29</b>
Legal capacity and mental capacity	31
Who is affected?	32
How does legal capacity, and deprivation of legal capacity, affect people's lives?	33
Coercive measures: involuntary treatment and placement	34
Women with disabilities	36
Models of substitute decision-making	38

Supported decision-making, will and preferences, and informed consent	40
Supported decision-making	40
Will and preferences of the person	43
Free and informed consent	44
Summary	46
<b>State of play in the European Union</b>	<b>47</b>
Legislation across the EU member states	48
Legal capacity regimes in the European Union	49
Development of supported decision-making systems	52
Ireland	54
Portugal	55
Spain	55
Greece	57
Powers of representation	58
Supported decision-making and continuing restriction of legal capacity	59
The role of the European Union	64
Cross-border protection of adults	65
Political participation	66
Summary	67
<b>Denial of legal capacity and human rights violations in Europe</b>	<b>68</b>
Gender perspective	70
Forced treatment and placement	71

Positive and negative examples from the European court of human rights	73
The council of Europe's draft additional protocol to the Oviedo convention	74
Forced sterilisation, abortion and contraception	76
Forced sterilisation in the European Union	77
Institutionalisation	80
Summary	83
<b>Promising practices</b>	<b>84</b>
Moving from substitute to supported decision-making	85
Sweden: personal ombud programme	86
Finland: open dialogue	87
Various countries: personal assistance budgets	88
Understanding and collecting free and informed consent	89
Training and material	89
Advance planning	90
Autonomy and support in mental health	92
Open dialogue approach	93
Summary	94
<b>Conclusions and recommendations</b>	<b>95</b>
European countries	97
European Union	98
Council of Europe	100

# This Human Rights Report is dedicated to Jolijn Santegoed and Sir Robert Martin



## In memory of Jolijn Santegoeds

"I know I have to stay true to myself, similarly as to when I was solitary confined in mental health care, I could not adapt to their standards which I considered fundamentally wrong (confinement is not care). I simply could not ignore my feeling of what is right and what is wrong. And in my past I already learned that standing up for myself may not be easy, and that my freedom may come at a price, yet, I find it worth it. Standing up against wrongs makes me feel like I am taking up my share in the collective responsibility for a fair and kind world. It feels good to do the right thing, and not let myself be fooled."

As a voice for persons with psychosocial disabilities – and lived experience – Jolijn’s activism touched many in the disability movement and beyond. We carry and try to emulate Jolijn’s example, always having time for people in need and using all channels possible to improve their lives.

The loss of Jolijn affects us all. We will continue Jolijn’s fight for a just world, one that does not put aside people with psychosocial disabilities. A world that is free of coercion, torture, and forced treatment. A world where everyone has the right to decide and control their lives.

Jolijn Santegoeds was an EDF board member, representative of the European Network of (ex) Users and Survivors of Psychiatry (ENUSP) and co-chair of the World Network of Users and Survivors of Psychiatry.



## In memory of Sir Robert Martin

We also want to pay tribute to the memory of Sir Robert Martin, who fought for the right to independent living for all persons with disabilities around the world.

Sir Robert made history as the first person with a learning disability elected to a United Nations treaty body when he joined the Committee on the Rights of Persons with Disabilities. He will be remembered as one of the great leaders of the disability movement in New Zealand and a trailblazing presence on the CRPD Committee.

[Back to Contents](#)



# Glossary

## A

### **Advance planning:**

advance plans (or advance directives) allow persons with disabilities to give instructions on how to deal with future personal crises, make decisions in advance if they cannot express their will and preferences in the future and/or appoint a person to support them in those circumstances.

## B

### **Best interest:**

paradigm, whereby another person or persons perceive what is considered as most appropriate for a person with a disability, irrespective of the individual's own will and preferences.

## C

### **Competences (of the European Union):**

areas within which the European Union (EU) can act, for instance by adopting legislation. Competences are defined by the EU treaties. In other areas, the EU Member States are competent to act.

### **Consent:**

permission/authorisation to something. Consent is “free and informed” when you have all the important information necessary to decide yourself, including to understand the consequences of your choice, and when you are not forced by another person to agree with something. Examples on deciding yourself can be about moving to a new place, to engage in sexual activity, or to undergo a medical treatment.

### **Council of Europe:**

Europe's leading human rights organisation. It includes 47 member states, 27 of which are members of the European Union. It is not related to the European Union.



**D****Disability:**

disability results from the interaction between persons with impairments (long term physical, mental, intellectual or sensorial) and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

**Discrimination:**

any distinction, exclusion or restriction on the basis of one or several grounds (sex, race, disability, sexual orientation, gender identity, etc.) which damages or nullifies the recognition, enjoyment or exercise of human rights and fundamental freedoms, on an equal basis with others, in the political, economic, social, cultural, civil or any other field.

**E****European Commission:**

the EU's executive arm. Its core responsibilities include proposing EU laws and policies and monitoring their implementation.

**European Court of Human Rights (ECtHR):**

the legal body that interprets the European Convention of Human Rights and its Protocols and adopts judgments by member states of the Council of Europe on cases alleging violations of these treaties.

**European Union (EU):**

a unique economic and political union between 27 European countries.

**G****General Comment:**

document prepared by experts of a United Nations (UN) body to explain the interpretation of a human rights treaty. General Comments often clarify what states need to do to respect and implement the articles of the treaty. The UN Committee on the Rights of Persons with Disabilities adopts General Comments to explain the UN Convention on the Rights of Persons with Disabilities.

**I Institutionalisation:**

placement of persons with disabilities (and sometimes other persons) in residential or care institutions and residences, because of lack of services and support for them to live in the community. This is a form of segregation and a human rights violation.

**L Legal capacity:**

the right to be recognised before the law and to make decisions and choices. This includes decisions to vote, have a medical treatment, sign an employment contract, go to court, own or inherit property, or get married, among many others.

**Member States (of the EU):**

the EU currently consists of 27 countries, also called “Member States”. Each Member State is party to the founding treaties of the European Union, and thereby subject to the privileges and obligations of membership. Unlike members of most international organisations, the Member States of the EU are subject to binding laws.

**M Mental capacity:**

decision-making skills or abilities of any person, which naturally vary from one person to another and may be different for a given person at different times, depending on many factors, including environmental and social factors.

**P Power of representation:**

power to represent another person or act on another person’s behalf in various areas, for example to make decisions regarding property, finances or medical care.

**S States Parties (of the CRPD):**

countries that have signed and ratified the CRPD and have committed to advance the rights of persons with disabilities. The European Union, having concluded the CRPD, is also a State Party together with all its Members States.

**Substitute decision-making:**

system that allows another entity (a person or an institution) to make decisions on behalf of a person whose legal capacity is removed. A substitute decision-maker is typically appointed by a court, guardianship authority, or other official body at the request of a third-party, such as a relative or the State. The terms “guardianship” and “curatorship” often refer to forms of substitute decision-making regimes. Although the terms are similar, their definition and rules vary across countries.

**Supported decision-making:**

system that provides the person with a disability with support to make decisions. Support in decision-making can take on a variety of forms, such formal and informal networks, support agreements, independent advocates, peer support, and/or advance directives (see definition above). The types of support can include access to information, support for communication, personal planning, independent living assistance, administrative support, among others. Those involved in support can be a “trusted person” or persons, such as family members, friends, peers, or individuals and/or professionals trained to provide support.

**U****United Nations CRPD Committee:**

the Committee on the Rights of Persons with Disabilities is the body of independent experts which monitors and reviews implementation of the Convention by the States Parties.

**United Nations Convention on the Rights of Persons with Disabilities (CRPD):**

an international human rights treaty that reaffirms that all persons with disabilities must enjoy all human rights and fundamental freedoms. It clarifies that all persons with disabilities have the right to participate in the civil, political, economic, social and cultural life of the community, the same as anyone else.

**United Nations Special Rapporteur:**

independent human rights expert whose expertise is called upon by the United Nations to report or advise on human rights from a thematic or country-specific perspective. The UN Special Rapporteur on the Rights of Persons with Disabilities works on disability rights.

**W****Will and preference:**

what a person wishes in that moment in time or for the future. Preferences, or what a person wants to do, comes from the person's values or cultural norms, knowledge and available information. Preferences are also influenced by past experiences and the consequences of previous decisions. Will and preferences can change from time to time.

[Back to Contents](#)

# Forewords for the EDF Human Rights Report on legal capacity



## **Sir Robert Martin**

Independent Expert, CRPD Committee member, Life Member of People First New Zealand Ngā Tāngata Tuatahi

Kia ora – Hello from New Zealand!

It is my pleasure to write a foreword for the EDF Human Rights report on legal capacity.

All disabled people have the right to enjoy legal capacity on an equal basis with others in all areas of life.

All disabled people want to be the decision makers of their own lives.

Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) is the obligation countries have, to make these right real.

I am very pleased the report has looked into how Europe is doing and what needs to happen to fully implement Article 12.

Sadly, while there are some promising practices, Europe still has a lot of work to do.

For me, Article 12 and supported decision-making is the central piece of the CRPD. This is because without having your legal capacity, you are treated as a non-human. Without having a say in your own life, other people decide everything about you, and you don't get the life you want.

Supported decision-making is important to many of us with a learning disability and to many other disabled people too. Many of my peers have had a lifetime of substituted decision-making. It is a breach of their rights and a grave injustice when a person is not included in the decision-making about their own life.

Much more needs to happen to make the rights in Article 12 real all around the world. I urge countries to look at the CRPD Committee's General Comment number one which gives more information about Article 12.

All countries need to make sure they are changing laws and practices that allow for the removal of legal capacity and for the provision of substitute decision-making – and replace them with systems that implement supported decision-making.

Education and training about what supported decision-making is and how to put it into practice is essential. This needs to be provided to politicians, health and educational professionals, people working in the media and the judiciary as well as to disabled people themselves and family members.

My hope is that this report is read all across Europe and inspires change. I look forward to hearing more about positive changes that countries in Europe are putting in place to fully implement Article 12 in the near future.

Kia kaha – stay strong!

**Sir Robert Martin KNZM**





## Senada Halilčević

### Self-advocate from Croatia and member of the EDF Women's Committee

Welcome to this report on legal capacity for people with disabilities.

My name is Senada Halilčević. I am a self-advocate from Croatia and member of the Women's Committee of the European Disability Forum.

In these pages, we explore an important topic that affects the lives of many individuals around the world.

Legal capacity means the ability to make decisions for yourself. Unfortunately, some people, especially those with intellectual disabilities, don't always have this ability recognised. Courts often decide whether someone can make their own decisions or if someone else, called a guardian, should make decisions for them.

For many people with disabilities, including many women with disabilities, this means losing control over important aspects of their lives. They may not be able to manage their money, decide where to live, or even make choices about their own bodies and health. In some places, like Croatia, women with disabilities might not be allowed to vote or run for political positions. They might also face involuntary medical procedures, such as sterilisation, without their consent.

This report highlights the importance of supporting people with disabilities, especially women and girls, to make their own decisions.

It calls for better laws and actions to ensure that everyone has the right to control their own lives, as outlined in the UN Convention on the Rights of Persons with Disabilities.

As you read through this report, let's keep in mind the real people whose lives are affected by these issues. Let's work together towards a future where everyone, regardless of ability, can live with dignity and make choices that matter to them.

**Senada Halilčević**



**Yannis Vardakastanis**

EDF President

A society cannot reach its full potential until everyone can participate in it.

This report shows that European societies are still far from reaching it, as the legal capacity of persons with disabilities – and their ability to participate in society – still faces shocking restrictions. Persons with disabilities in Europe are treated as second-class citizens, with unequal rights, unequal opportunities and a lack of support to decide about their lives.

When the United Nations Convention on the Rights of Persons with Disabilities was adopted, States committed to ensuring that the right to equality before the law and legal capacity applies to everyone. Yet, as we are approaching the 20-year anniversary of the Convention we don't see this in practice. We still see exceptions. We still see governments that do not understand the right to decide. We still see a wide lack of measures to support people in leading their lives.



As countries around the world implement groundbreaking reforms (countries such as Mexico or Costa Rica), European countries remain reluctant and conservative. They refuse to ensure a simple right to persons with disabilities: the right to live like others.

A simple right that grants people power over their lives. Power to decide where to live, to sign a contract, to marry whoever they wish. The power to be involved in decisions and policies that affect their lives.

Many persons with disabilities – and especially those with intellectual and psychosocial disabilities – are left powerless by the States. This has grievous consequences and leads to a multitude of human rights violations, including segregation, coercion, violence and abuse.

2024 will usher in new legislatures, not only in the European Parliament but in many EU countries as well. It is time for Europe to step up and ensure that persons with disabilities can live full, independent lives. This Human Rights Report serves also as a call to action: make equality before the law a reality in this new political mandate.

A change that will assert and amplify our motto: from “Nothing about us without us” to “Nothing without us”.

**Yannis Vardakastanis**





## Tamara Byrne

### EDF Youth Committee Member

My name is Tamara Byrne and I am a self-advocate from Ireland. I am a member of the European Disability Forum Youth Committee. I am the first ever member with an intellectual disability.

This report is about a very important topic. It is all about legal capacity for people with disabilities.

Legal capacity means how much power someone has, to make legal decisions for themselves.

Legal decisions could be about very important things in your life like medical treatment, marriage, housing, getting a job, or managing your own money.

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities says that we have the right to the same legal capacity as everyone else.

This topic is important to young people with intellectual disabilities because we are often treated like children even if we are over 18.

These attitudes in society are a big barrier for people with intellectual disabilities and stop us from getting independence.

Everybody needs a bit of support in life.

If I need information explained in a different way it doesn't mean I should not get to make choices about my own life. It just means the information needs to be available in accessible ways. This foreword is in Easy to Read which makes it easier to understand.

If you disagree with my choices that doesn't mean you can take my choice away from me, in the same way that I cannot tell you what to do with your life.

In 2023 Ireland made a big step forward by getting rid of the old 1861 Lunacy Act and putting in the Assisted Decision-Making (Capacity) Act.

Now people can be empowered to make their own decisions and can get whatever type of support they want, to make decisions from the Decision Support Service. This government body was only set up last year, but I hope that it will help people with intellectual disabilities in Ireland to make their own decisions in life.

Ireland has come a long way but until we treat disabled people as an equal part of society, we still have a lot more to do.

You will see in the report that there are still some European countries who are very much behind on this.

In some countries like France, Italy, Greece and others, some people with disabilities have no rights to make legal decisions about their own lives.

This is not right and needs to be changed as soon as possible.

I love working with my colleagues in the EDF Youth Committee.

We are all from different countries in Europe, so we can share different experiences from our countries and work together to change things at the European level.

We are all equal, so we should all have the same rights when we go back to our home countries.

In the near future, I hope to see a Europe where all people with disabilities will have the same rights as me, no matter what country they are living in. I hope the report will inspire you to help us work towards that future.

**Tamara Byrne**

[Back to Contents](#)



# Executive Summary

**Legal capacity is an essential right that allows everyone to make choices, take decisions and have control over their lives and bodies.**

This is a right protected by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) ratified by the European Union (EU) and all its Member States. It is also a necessary condition to enjoy many other human rights of persons with disabilities.

Our Human Rights Report finds that no EU Member State fully complies with the right to legal capacity as required by Article 12 of the CRPD.

All of them still provide for ways to deprive a person with a disability of their legal capacity, either completely or partly.

- 12 EU Member States still allow full deprivation of legal capacity in their law: **Bulgaria, Croatia, Cyprus, Denmark, Estonia, France, Greece, Hungary, Italy, Luxembourg, Netherlands and Poland.** People are denied the right to make all choices.
- 9 EU Member States provide partial guardianship and similar systems: **Belgium, Finland, Latvia, Lithuania, Malta, Romania, Slovakia, Slovenia and Sweden.** The right to decide can be partly limited to specific areas, for example when it comes to spending money or signing a contract.
- 6 EU Member States have almost fully abolished guardianship, but still keep some exceptions in a few cases and for some persons with disabilities: **Austria, Czechia, Germany, Ireland, Portugal and Spain.** In theory, people with disabilities cannot be deprived of their legal capacity, but courts can make exceptions when they consider that the person cannot make a decision in a specific area, and/or for a limited period of time.

Some Member States have developed formal and informal supported decision-making systems to respect better the rights, choice and autonomy of persons with disabilities. We identified 13 EU Member States that have supported decision-making systems established by law: **Austria, Belgium, Czechia, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Portugal, Spain and Sweden.** In other countries, supported decision-making programmes may operate, even though without legal guarantees to that form of support. Some promising practices include personal advocates, open dialogue and personal assistance budgets, as well as practices to understand and collect free and informed consent, and to ensure autonomy in mental health care.

The report also finds that the European Union and the Council of Europe, including its European Court of Human Rights, still fail to adopt measures to promote and protect the legal capacity, and more broadly, the autonomy and right to choose, of persons with disabilities.

Much remains to be done to ensure the right to legal capacity for all. Strong actions are needed at all levels of policymaking: from the EU and the Council of Europe to European countries who have the ultimate power to change their laws and policies to finally ensure that persons with disabilities are not denied the right to decide and control how to live their lives.

[Back to Contents](#)



# Introduction

This 8th edition of the European Disability Forum's [Human Rights Report series](#) focuses on the legal capacity of persons with disabilities. The report explores the many barriers faced by persons with disabilities in the exercise of their legal capacity and the numerous fundamental rights violations that come with restricting this key right.

Since the ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD), denial of legal capacity, restriction of autonomy and control over the lives of persons with disabilities are among the most widespread human rights violations faced by persons with disabilities around Europe and the world. Those with intellectual and/or psychosocial disabilities are particularly affected.

As highlighted in our [6th Human Rights Report on political participation](#), deprivation of legal capacity can impact the right to vote and stand for elections for persons with disabilities in many countries. In addition, it impacts the right to make any and every decision in one's life, like opening a bank account, deciding where to live, buying a service or property, deciding to marry, and so on. It also enables additional human rights violations, especially in the area of health care, such as involuntary treatment and placement, forced sterilisation, as well as institutionalisation.

This Human Rights Report aims to:

- 1. Explain the right to legal capacity and key obligations under the CRPD.**
- 2. Present up-to-date information on legal capacity across the EU Member States, including laws, as well as new measures and policies put in place to support persons with disabilities in exercising their legal capacity.**
- 3. Reveal how deprivation of legal capacity is linked to coercion and control over persons with disabilities.**
- 4. Share promising practices on supported decision-making, collecting free and informed consent and voluntary support in mental health.**
- 5. Provide recommendations for the Council of Europe, the European Union and Member States.**

The report is structured as follows.

**Chapter 1** is common to each issue of the EDF's Human Rights Report series; in it, we outline general progress on the CRPD in Europe and highlight which European countries are failing to meet their basic obligations.

**Chapter 2** explains what legal capacity is, who is affected, the distinction between mental capacity and legal capacity, models of substitute and supported decision-making regimes, and how legal capacity affects people's lives.

**Chapter 3** presents a state of play of the legal capacity laws in EU Member States. It looks at the legislation across Europe and how it complies with the CRPD. It also covers the development of supported decision-making systems.

**Chapter 4** focuses on how denial of legal capacity leads to a variety of human rights violations across Europe.

**Chapter 5** describes promising practices from different countries on better compliance with the CRPD, from moving from substitute to supported decision-making regimes, to obtaining consent and ensuring autonomy and choice in mental health care.

**Chapter 6** draws conclusions and offers recommendations for European countries, the EU and the Council of Europe.

## Methodology

This report was prepared by the Secretariat of the European Disability Forum under the guidance of its Human Rights and Non-Discrimination Committee, Board of Directors and with input from its members.

Research was conducted and data collected by Jane Buchanan, consultant.

[Back to Contents](#)

## Chapter 1:

# CRPD update in Europe





The CRPD is an international human rights treaty reaffirming that persons with disabilities enjoy all human rights and fundamental freedoms.

It was adopted in 2006 by the General Assembly of the United Nations (UN). 191 countries, including the European Union (EU), are States Parties to the CRPD. It is also the world's fastest-ratified international human rights treaty.<sup>1</sup>

This Convention clarifies that persons with disabilities have the right to participate in civil, political, economic, social and cultural life in the community, just like anyone else. It stipulates what public and private authorities must do to ensure and promote the full enjoyment of these rights by all persons with disabilities.

The right to equality before the law is addressed in Article 12 of the Convention.<sup>2</sup>

## Ratification of the CRPD

In Europe, the CRPD was ratified rapidly.

The EU is a State Party to the CRPD since 2011. By March 2018, all EU Member States and the EU have ratified the Convention. It is the first time that there has been universal ratification of an international human rights treaty in the EU.

Other countries in Europe that have ratified the CRPD include **Albania, Andorra, Armenia, Azerbaijan, Georgia, Iceland, Moldova, Monaco, Montenegro, North Macedonia, Norway, San Marino, Serbia, Switzerland, Turkey and Ukraine.**

**Liechtenstein** was the last European country to ratify the CRPD in December 2023. EDF welcomes its ratification.

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- 1 See the United Nations' overview of countries that have ratified the CRPD: [https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-15&chapter=4](https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4).
  - 2 Article 12 of the CRPD on "Equal recognition before the law", <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>.

## Submission of initial report to the CRPD Committee

States Parties are obliged to submit an initial report to the CRPD Committee on the measures taken to implement the Convention two years after the CRPD comes into force in their country.

**San Marino** is the last State Party in Europe that has not submitted its initial report to the CRPD Committee, thereby blocking the Committee's review process on progress made towards the implementation of the CRPD. The state report was due 22 March 2010.

**EDF calls on San Marino to urgently submit its initial state report to the CRPD Committee.**



**■ State Party that has not submitted its initial report to the CRPD Committee:**

1. San Marino

# Ratification of the Optional Protocol to the CRPD

The Optional Protocol to the CRPD allows individuals, groups of individuals, or third parties to submit a complaint to the CRPD Committee about human rights violations. Complaints may only be made against a State Party that has ratified the Optional Protocol. If the CRPD Committee finds that the State Party has failed in its obligations under the CRPD, it will issue a decision requiring that the violation be remedied and for the State Party to provide follow-up information.

22 EU Member States have ratified the Optional Protocol.

The EU and the following Member States have not ratified the Protocol: **Bulgaria, Ireland, Netherlands, Poland** and **Romania**.

In addition, **Albania, Iceland, Liechtenstein, Norway** and **Switzerland** have not ratified it.

The CRPD Committee calls on each State Party to ratify the Optional Protocol.

**EDF calls on the EU, as well as Albania, Bulgaria, Iceland, Ireland, Liechtenstein, Netherlands, Norway, Poland, Romania and Switzerland, to ratify the Optional Protocol.**



**Countries that did not ratify the Optional Protocol to the CRPD:**

- |                  |                 |
|------------------|-----------------|
| 2. Albania       | 7. Netherlands  |
| 3. Bulgaria      | 8. Norway       |
| 4. Iceland       | 9. Poland       |
| 5. Ireland       | 10. Romania     |
| 6. Liechtenstein | 11. Switzerland |

[You can read the full text of the CRPD and the Optional Protocol on the web page of the CRPD Committee.](#)

[Back to Contents](#)

## Chapter 2:

# What is legal capacity?



Legal capacity is the right to be recognised before the law, to make choices and to speak on one's behalf. It is an inherent right of all people, equally and everywhere. The right to equality before the law is a fundamental principle of human rights and essential for the exercise of civil, political, economic, social and cultural rights.

However, throughout history, legal capacity has been denied to many groups, including women, ethnic minorities and persons with disabilities. Denial of legal capacity uses the law to reinforce social prejudices and perpetuates exclusion as well as human rights abuses.

Article 12 of the CRPD affirms that “persons with disabilities have the right to recognition everywhere as persons before the law” without discrimination, or “on an equal basis with others in all aspects of life”.<sup>1</sup> The Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) also guarantee equality before the law.<sup>2</sup>

The enjoyment of legal capacity – to make one's own decisions and have them respected by others – is key to accessing meaningful participation in society. This includes decisions to vote, to sign an employment contract, to go to court, to own or to inherit property, to have children or to not have children, to get married, or consenting to medical treatment, among many others.<sup>3</sup> It also includes the freedom to make decisions even when they seem unreasonable or risky to others and to learn from mistakes.

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1 Convention on the Rights of Persons with Disabilities (CRPD), General Assembly Resolution A/RES/61/106, adopted 12 December 2006, entered into force 3 May 2008, Art. 12.

2 Universal Declaration of Human Rights, General Assembly Resolution A/RES/217(III), 10 December 1948, Art. 6; and International Covenant on Civil and Political Rights (ICCPR), General Assembly Resolution 2200A (XXI), adopted 16 December 1966, entered into force 23 March 1976, Art. 16; and Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), General Assembly Resolution A/ RES/34/180, adopted 18 December 1979, entered into force 3 September 1981, Art. 15.

3 Committee on the Rights of Persons with Disabilities (CRPD Committee), General Comment No. 1, para. 8.

The exercise of legal capacity also means that others are prohibited from making decisions on behalf of a person with disabilities, known as substitute decision-making. Substitute decision-making involves legal systems that designate someone other than the individual with a disability to make legally binding decisions about their life, such as guardianship laws, as well as mental health laws that allow involuntary treatment and placement.<sup>4</sup> Instead, persons with disabilities are entitled to “the support they may require in exercising their legal capacity”, as described below.<sup>5</sup>

## Legal capacity and mental capacity

Legal capacity and mental capacity are different concepts.

Legal capacity is an inherent, inalienable right, consisting of the right to hold rights and duties (legal standing) and the right to exercise those rights and duties (legal agency).

“Mental capacity” refers to the decision-making skills or abilities of a person. It naturally varies from one person to another and may be different for a given person at different times, depending on many factors, including environmental and social factors. The concept of “mental capacity” and any tests to measure it are flawed because the way people make decisions cannot be measured scientifically.<sup>6</sup>

The CRPD Committee notes that “concepts of mental and legal capacity have been conflated [by governments], so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed”,

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4 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), A/HRC/37/56, 12 December 2017, para. 26.

5 CRPD, Art. 12.

6 CRPD Committee, General Comment No. 1, para. 13; and World Health Organisation, “Legal Capacity and the Right to Decide Course Guide – WHO QualityRights Core training: mental health and social services”, <https://apps.who.int/iris/bitstream/handle/10665/329539/9789241516716-eng.pdf?sequence=1&isAllowed=y>.

which constitutes discrimination against persons with disabilities.<sup>7</sup> Any claims of “unsoundness of mind” and other discriminatory labels are not legitimate reasons for the denial of legal capacity.<sup>8</sup>

## Who is affected?

Persons with all types of disabilities can be subject to denial of legal capacity.

However, some groups are more at risk:

- Persons with intellectual or psychosocial disabilities, as well as persons with complex support requirements.<sup>9</sup>
- Women with disabilities are at serious risk of deprivation of their legal capacity.<sup>10</sup> They often experience higher rates of substitute decision-making than men.<sup>11</sup> This happens in addition to often experiencing multiple and intersectional forms of discrimination based on gender and disability, as well as gender-based violence.
- Older persons, especially older persons with some condition (such as dementia) that lead to a disability are also particularly at risk of being subjected to substitute decision-making owing to prejudices and assumptions based on both age and disability.<sup>12</sup>

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7 CRPD Committee, General Comment No. 1, para. 15.

8 CRPD Committee, General Comment No. 1, para.13.

9 CRPD Committee, General Comment No. 1, para. 9; and “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity).

10 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), para. 17.

11 CRPD Committee, General Comment No. 1, para. 35.

12 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), para. 5.



# How does legal capacity, and deprivation of legal capacity, affect people's lives?

The right to legal capacity concerns all aspects of life. Restrictions and limitations on legal capacity deny people the right to make their own decisions, leaving them with little or no control over some or all aspects of their lives.

Deprivation of legal capacity infringes on the full scope of inalienable human rights, including freedom from torture or cruel, inhuman or degrading treatment or punishment; freedom from exploitation, violence and abuse; freedom of expression and opinion. It also deprives persons with disabilities of their rights to access to justice; liberty and security of the person; living independently and being included in the community; access to information; privacy; marriage, family, parenthood and relationships; health, including the right to free and informed consent and sexual and reproductive health and rights; work and employment; and participation in political and public life, such as voting or holding office, among others.<sup>13</sup>

In our Human Rights Report on political participation, we explain how some European countries still restrict the right to vote of persons with disabilities under guardianship.<sup>14</sup>

Legal capacity restrictions also “perpetuate discrimination and exclusion against persons with disabilities and pave the way to different forms of abuse, corruption, exploitation, coercion, and institutionalisation”.<sup>15</sup>

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13 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), para. 25.

14 European Disability Forum, 6th Human Rights Report 2022: political participation of persons with disabilities, 2022, <https://www.edf-fehp.org/publications/human-rights-report-2022-political-participation-of-persons-with-disabilities/>.

15 Inclusion Europe, “The Right to make decisions”, undated, <https://www.inclusion-europe.eu/wp-content/uploads/2018/10/Legal-capacity-and-empowerment.pdf>.

## Coercive measures: involuntary treatment and placement

Due to discriminatory laws and practices, in particular mental health laws, persons with disabilities around the world and in Europe – particularly those with psychosocial and intellectual disabilities – can be subject to forced treatment and forced placement in psychiatric hospitals, institutions, or similar facilities, denying the legal capacity of a person and their right to choose medical treatment based on their free and informed consent. Mental health laws, which allow for forced treatment, are understood as substitute decision-making measures, because clinicians and other individuals make decisions and provide consent on behalf of persons with disabilities.<sup>16</sup>

Forced treatment most frequently involves the administration of medication, in some cases strong psychotropic medication, and the use of mechanical and physical restraints and seclusion. Forced treatment can violate individuals' rights to personal integrity; freedom from torture; freedom from violence, exploitation and abuse; and the right to the highest attainable standard of health.<sup>17</sup>

"I had two crises – the first in 2000, the second in 2005. Then nobody asked me, they talked to my mother and she gave consent and signed the document but nobody had explained to me what exactly electroconvulsive therapy is like. Initially I thought it was anaesthesia which helps the medication to reach all parts of the body, but after that I realised it is not this."

Woman, 29, Bulgaria<sup>18</sup>

16 Sugiura K., Mahomed F., Saxena S., Patel V., "An end to coercion: rights and decision-making in mental health care", *Bulletin of the World Health Organisation*, 1 January 2020; 98(1):52-58.

17 CRPD Committee, General Comment No. 1, para. 42.

18 Fundamental Rights Agency of the European Union, "Involuntary placement and involuntary treatment of persons with mental health problems", 2012.

Placement of persons with disabilities in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is a denial of legal capacity and also constitutes arbitrary deprivation of liberty, in violation of Article 14 of the CRPD.<sup>19</sup> As described below, persons with disabilities confined against their will, including in residential institutions, often also experience inhuman and degrading conditions of detention, violence, sexual violence, humiliation, and other forms of physical, mental, and emotional abuse. The deprivation of legal capacity and the lack of direct access to the justice system often means that people are unable to challenge their institutionalisation and leave institutions because of their guardians' power, impeding their right to live independently in the community.<sup>20</sup>

“They probably injected me in the hand but I don’t remember now and I fell immediately asleep; my eyes closed. Right after they did electric shocks without me knowing about it. I found out later. They ruined my life.”

**Man, 55, Greece**<sup>21</sup>

Many persons with disabilities experience deep, lasting psychological and physical harm and trauma as a result of coercive measures.<sup>22</sup> Furthermore, academic and other research has found that coercive interventions in mental health care continue to be used extensively, despite the fact that research does not suggest they are

19 CRPD Committee, General Comment No. 1, paras. 40-41.

20 See for example: CRPD Committee, “Inquiry Concerning Hungary under Article 6 of the Optional Protocol to the Convention”, 17 September 2020, [https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f%20HUN%2fIR%2f1&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f%20HUN%2fIR%2f1&Lang=en).

21 Fundamental Rights Agency of the European Union, “Involuntary placement and involuntary treatment of persons with mental health problems”, 2012.

22 CRPD Committee, General Comment No. 1, para. 42; and World Network of Users and Survivors of Psychiatry, “Human Rights Position Paper,” 2001, <https://wnusp.wordpress.com/wp-content/uploads/2016/05/human-rights-position-paper-of-the-world-network-of-users-and-survivors-of-psychiatry.pdf>; and Sugiura K. et al., “An end to coercion: rights and decision-making in mental health care”; and Sashidharan S.P., Mezzina R., Puras D., “Reducing Coercion in Healthcare”, *Epidemiology of Psychiatric Science*, December 2019, 28(6):605-612, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7032511/>.

clinically effective or result in better clinical or social outcomes.<sup>23</sup> The continued use of these methods, which are not proven to be effective and which actually cause grievous harm rather than promoting improved health and well-being, is a serious, continuing practice that abuses human rights and which European states should eliminate immediately.

## Women with disabilities

For women with disabilities, deprivation of legal capacity can have particularly negative impacts, among other things due to multiple, intersecting forms of discrimination. It can infringe on their rights to marry and start a family; give or withhold consent to intimate relationships; decide where and with whom to live; own and inherit property, and control their own financial affairs; seek accountability for various forms of abuse through the justice system and participate in all other daily aspects of civil, political, cultural, economic, and social life; and their right to physical and mental integrity.<sup>24</sup>

Women with disabilities who marry are at even greater risk of losing their legal capacity.<sup>25</sup>

Significantly, when deprived of their legal capacity, women with disabilities cannot make autonomous decisions about – and thus have no control over – their reproductive and sexual health and rights, resulting in highly discriminatory and harmful practices.<sup>26</sup> Women with disabilities are frequently subjected to sexual and reproductive health procedures without their consent, including forced sterilisation, forced abortion and forced contraception, due

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23 Sashidharan S.P. et al., “Reducing Coercion in Healthcare”.

24 Women Enabled International, “Legal Capacity of Women and Girls with Disabilities”, Fact Sheet, no date, <https://womenenabled.org/wp-content/uploads/2021/02/Women-Enabled-International-Legal-Capacity-of-Women-and-Girls-with-Disabilities-English.pdf>; and World Health Organisation (WHO), “Legal Capacity and the Right to Decide Course Guide: WHO QualityRights Core training: mental health and social services”.

25 CRPD Committee, General Comment No. 1, para. 18.

26 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), para. 17.

to misconceptions that they are asexual or incapable of making informed decisions about their health and bodies.<sup>27</sup>

Women with disabilities can be pressured to end their pregnancies owing to negative stereotypes about their parenting skills and eugenics-based concerns about giving birth to a child with disabilities.<sup>28</sup>



### Forced sterilisation

United Nations human rights instruments, mechanisms and agencies have recognised that the forced sterilisation of persons with disabilities constitutes discrimination, a form of violence, torture and other cruel, inhuman or degrading treatment. Forced sterilisation and forced abortion are also prohibited under the Council of Europe Convention on preventing and combating violence against women and domestic violence (also called “Istanbul Convention”).<sup>29</sup> However, the practice is still legal and applied in many countries and disproportionately impacts girls and young women with disabilities, particularly those with intellectual and psychosocial disabilities and those placed in institutions. Legal systems allow judges, health care professionals, family members and guardians to consent to sterilisation procedures on behalf of persons with disabilities.<sup>30</sup>

27 Women Enabled International, “Legal Capacity of Women and Girls with Disabilities”, Fact Sheet.

28 “Report of the Special Rapporteur on the Rights of Persons With Disabilities: Sexual and reproductive health and rights of girls and young women with disabilities”, A/72/133, 14 July 2017, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>.

29 Council of Europe Convention on preventing and combating violence against women and domestic violence, Article 39, <https://rm.coe.int/168008482e>.

30 “Report of the Special Rapporteur on the Rights of Persons with Disabilities: Sexual and reproductive health and rights of girls and young women with disabilities”, A/72/133. See the concluding observations of the Committee on the Rights of Persons with Disabilities in relation to the reports of Croatia, Czechia, Germany, Hungary, Lithuania, Mauritius, Portugal, Slovakia, Spain, Ukraine and the European Union.

Women with disabilities experience heightened rates of forced institutionalisation compared to men with disabilities and women without disabilities, and women who have been institutionalised seldom have the legal right to challenge their institutionalisation.<sup>31</sup>

## Models of substitute decision-making

When a person with a disability is deprived of their legal capacity, whether for all decisions or only for some, another individual is given the right to make decisions for them. They are called a “substitute decision-maker”.

A **substitute decision-maker** is typically appointed by a court, guardianship authority, or other official body at the request of a third-party, such as a relative.

The decision to appoint a substitute decision-maker is based on medical or other assessments, for example regarding a person’s so-called “mental capacity”, “mental impairment”, “mental disorder”, “inability to understand their actions”, and/or “inability to care for themselves”. Appointment of a guardian can be done against the will of the person concerned and, in some cases, without their knowledge. The substitute decision-maker is required to decide based on the “best interests” of the person concerned, rather than the person’s own will and preferences, as required under the CRPD.<sup>32</sup>

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31 “Report of the Special Rapporteur on the Rights of Persons with Disabilities: Sexual and reproductive health and rights of girls and young women with disabilities.”

32 CRPD Committee, General Comment No. 1, para. 27.



### “Best interest” paradigm

The notion of best interests is found in the UN Convention on the Rights of the Child. Article 3 of the Convention says that “in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration”. Assessing the best interests of a child means to evaluate and balance “all the elements necessary to make a decision in a specific situation for a specific individual child or group of children”.

The concept of best interests is sometimes still applied to adults with disabilities, often based on a paternalistic approach to persons with disabilities.

The CRPD challenges the traditional application of the “best interest” paradigm to persons with disabilities, as it can often be used to justify decisions made on behalf of individuals with disabilities without their input or consent. Instead, the convention promotes a paradigm shift towards supported decision-making, where individuals with disabilities are provided with the necessary support to make decisions based on their own preferences and values, rather than having decisions made for them based on what others perceive to be in their best interests.

There are different models of substitute decision-making around the world and in Europe. These include **full guardianship**, also known as plenary guardianship. Also common is **partial guardianship**, whereby substitute decision-making should formally be limited to certain areas determined by the court or other appointing agency. Some states use terms as wardship or tutorship for full guardianship systems and curatorship, mentorship or other terms for partial guardianship.



### Full guardianship

Under full guardianship, the individual's legal capacity to make decisions is significantly restricted, and the guardian assumes the responsibility for making decisions on behalf of the individual. The guardian typically has broad authority to make decisions in various areas of the person's life, including financial matters, medical treatment, living arrangements, and personal affairs.

As described in more detail below, substitute decision-making also occurs under mental health laws that permit forced treatment and placement in psychiatric hospitals or institutions based on assumptions such as "risk to self or others", "need for treatment", "presumed danger", or "lack of insight".

**Informal substitute decision-making** happens when an individual, such as family members or others, make decisions on behalf of an individual with disabilities, even if they are not formally recognised as a guardian.

## Supported decision-making, will and preferences, and informed consent

### Supported decision-making

Rather than depriving persons with disabilities of their legal capacity, the CRPD requires States Parties to ensure the availability of support for people to help them make decisions, called supported decision-making.

This support should guarantee the person's human rights and ensure they retain control over their lives. It is founded on the principles of respect for the individual's autonomy, will and preferences. Ensuring



access to support in the exercise of legal capacity enables States to guarantee the right to equal recognition of all persons before the law. As noted above, it is guaranteed by the CRPD, the CEDAW, the International Covenant on Civil and Political Rights, and the Universal Declaration on Human Rights.<sup>33</sup>

Support in decision-making can take on a variety of forms. These can be formal and informal networks, support agreements, independent advocates, peer support and/or advance directives. The types of support can include access to information, support for communication, personal planning, independent living assistance and administrative support, among others. Those involved in this support can be a “trusted” person or persons, such as family members, friends or peers. In other cases, supporters are individuals and/or professionals trained to provide support. There can also be a mixed approach with trained individuals providing guidance to trusted persons.<sup>34</sup>

The CRPD Committee has set out specific provisions regarding rights-respecting supported decision-making and, as part of its QualityRights initiative, the World Health Organisation (WHO) provides extensive guidance and training on legal capacity and supported decision-making.<sup>35</sup>

Supported decision-making must be voluntary, directed by the person with disabilities and available to all, irrespective of an individual’s support needs and a person’s mode of communication, even where this communication is non-conventional or understood by very few people.<sup>36</sup>

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33 CRPD, Art. 12.3.

34 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), para. 54, 56. See also: European Network of National Human Rights Institutions (ENNHRI) and Mental Health Europe (MHE), “Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs”, 8 June 2020, <https://www.mhe-sme.org/wp-content/uploads/2020/06/Report-ENNHRI-and-MHE-Implementing-supported-decision-making.pdf>.

35 World Health Organization (WHO), “QualityRights materials for training, guidance and transformation”, November 2019, <https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools>. Including for example: “Supported decision-making and advance planning. WHO QualityRights Specialized training. Course guide”, 2019, Geneva.

36 CRPD Committee, General Comment No. 1, para. 29.

A supporter cannot be appointed by a third party against the will of the person concerned.<sup>37</sup> Crucially, the individual with disabilities must have control over the support available, including the right to select supporters, to refuse support, and to terminate or change the support relationship at any time.<sup>38</sup> Support must be flexible and specific to the individual.<sup>39</sup> Experts also note the importance of accepting risk-taking, and the “dignity of risk”, whereby the individual’s right to decide is accepted, even if a decision may seem risky or unreasonable to others.<sup>40</sup>

Governments must also ensure appropriate safeguards, such as regular independent legal review, including to prevent undue influence and abuse.<sup>41</sup>

Support systems must also ensure a mechanism for third parties to verify the identity of a support person as well as a mechanism to challenge the action of a support person if they believe that they are not acting in accordance with the will and preferences of the person.<sup>42</sup>

Consistent with the recognition that mental capacity is never a constant, knowable state of a person’s ability to make decisions, provision of support in decision-making should not hinge on mental capacity assessments, and these assessments should be eliminated altogether.<sup>43</sup>

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37 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), para. 27.

38 CRPD Committee, General Comment No. 1, para. 29.

39 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), paras. 27, 56.

40 ENNHRI and MHE, “Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs”.

41 CRPD, Art. 12.4; and CRPD Committee, General Comment No. 1, para. 29(h). Measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

42 CRPD Committee, General Comment No. 1, para. 29.

43 CRPD Committee, General Comment No. 1, para. 29.

## Will and preferences of the person

One of the most central elements of any form of supported decision-making is that it must consistently reflect and respond to the will and preferences of the person utilising support.<sup>44</sup> According to the CRPD Committee, respect for the “will and preferences” of each individual must replace the “best interest” paradigm ([explained in the box on page 39](#)).<sup>45</sup>

In a resolution on Mental Health and Human Rights, the UN Human Rights Council called upon governments to “abandon all practices that fail to respect the rights, will and preferences of all persons, on an equal basis”.<sup>46</sup>



### Respecting the will and preferences of the person

In cases when the will of a person with a disability might be difficult to determine, States must have mechanisms in place to undertake significant efforts to determine a person’s will and preferences. If all attempts to do so have been exhausted, then a “best interpretation of the will and preference” standard should be applied as a last resort. This means ascertaining what the person would have wanted, based on the person’s previous choices, values, attitudes and actions. It is not the same as making decisions based on the “best interest” of the person with the disability.<sup>47</sup>

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44 CRPD, Art. 12.4.

45 CRPD Committee, General Comment No. 1, para. 29.

46 United Nations Human Rights Council, Resolution on Mental Health and Human Rights, A/HRC/36/L.25, 2017.

47 “Report of the Special Rapporteur on the Rights of Persons with Disabilities” (on legal capacity), para. 31.

## Free and informed consent

Consent refers to voluntary agreement as the result of a person's free will. Examples of consent can be to move to a new place, to have sexual activity, or to accept a medical treatment.

The decisions that affect the lives of persons with disabilities must be based on their free and informed consent. Denial of legal capacity has led to many violations, including exceptions to this rule of free and informed consent, especially in the area of health care.

The United Nations International Covenant on Economic, Social and Cultural Rights asserts the right to the highest attainable standard of health, which includes control over one's health and the right to be free from non-consensual medical treatment.<sup>48</sup> The CRPD guarantees persons with disabilities the right to health without discrimination on the basis of disability, and also specifies that treatment should be provided only on the basis of free and informed consent.<sup>49</sup> This is essential to exercising the right to legal capacity.

Informed consent involves the provision of accurate and accessible information about service options, risks and benefits, as well as available alternatives, such as non-medical approaches.<sup>50</sup> Consent must be free of threat or coercion, including threats of involuntary placement if treatment is declined, and it must be free of undue influence and deception. The right to informed consent also includes the right to refuse treatment. In mental health and social services, there can be risks of undue influence due to power imbalances between providers and persons with disabilities. Therefore, support for decisions should come from outside the service in order to minimise the risk of undue influence or coercion.<sup>51</sup>

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48 International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted 16 December 1966, General Assembly Resolution 2200A (XXI), **entered into force 3 January 1976**, Art. 12.

49 CRPD, Art. 25; and CRPD Committee, General Comment No. 1, para. 41.

50 CRPD Committee, General Comment No. 1, para. 42.

51 WHO, "Legal Capacity and the Right to Decide. WHO QualityRights Core training: mental health and social services".

The right to free and informed consent for medical care, mental health services, and admission to institutions is frequently violated in relation to persons with disabilities, particularly those with psychosocial disabilities. Decisions made by clinicians, family members or others, are prohibited by the CRPD, even if they consider to be acting in the supposed “best interest” of the person with disabilities. This includes decisions regarding any kind of medical care, medication, and placement in institutions.<sup>52</sup> The Human Rights Council has called on states to provide mental health services “on the same basis as to those without disabilities, including on the basis of free and informed consent”.<sup>53</sup>

Forced treatment, or treatment without consent, is not only a violation of the right to legal capacity but also violates the rights to personal integrity, freedom from torture, and freedom from violence, exploitation and abuse.<sup>54</sup>

All governments must ensure that medical providers and others respect the decisions of persons with disabilities and should guarantee systems that provide the necessary support in decisions regarding medical treatment to ensure free and informed consent, including in crisis situations.

There is also growing evidence on the effectiveness of non-coercive support practices, as described in Chapter 5 below.<sup>55</sup>

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52 CRPD, Art. 25; and CRPD Committee, General Comment No. 1, para. 41. The UN Special Rapporteur on the right to health has also stated: “States must not permit substitute decision-makers to provide consent on behalf of persons with disabilities on decisions that concern their physical or mental integrity; instead, support should be provided at all times for them to make decisions, including in emergency and crisis situations.”

53 United Nations Human Rights Council, Resolution on Mental Health and Human Rights, 2017.

54 CRPD Committee, General Comment No. 1, paras 41 and 42.

55 General Assembly, Report of the UN Special Rapporteur on the Rights of Persons with Disabilities, A/HRC/37/56, 12 December 2017, para. 32.

## Summary

- Many systems in place focus on substitute decision-making and wrongful notions of “best interest” that lead to abuse and human rights violations.
- Persons with intellectual disabilities, persons with psychosocial disabilities, older persons, and women with disabilities are at special risk of abuse.
- Forced treatment, forced sterilisation and coercion in health care are especially pervasive and dangerous.
- Supported decision-making mechanisms need to be put in place to ensure the right to legal capacity of persons with disabilities.
- States must ensure the correct provision of support, mechanisms to guarantee independent analysis of support and means to seek redress.

[Back to Contents](#)

## Chapter 3:

# State of play in the European Union



## Legislation Across the EU Member States

Despite reforms regarding guardianship, legal capacity and supported decision-making in several EU countries in recent years, many still allow for guardianship, even when supported decision-making systems exist. Additionally, all EU Member States retain some form of substitute decision-making under law, which violates individuals' right to legal capacity and contravenes Member States' obligations under the CRPD.<sup>1</sup>

Four EU Member States, **Estonia, Ireland, Netherlands** and **Poland** have issued declarations and reservations regarding Article 12 of the CRPD, asserting that they will interpret Article 12 to allow for deprivation of legal capacity. For example, Netherlands states that it "interprets Article 12 as restricting substitute decision-making arrangements to cases where such measures are necessary, as a last resort and subject to safeguards". Estonia declares that it "interprets article 12 of the Convention as it does not forbid to restrict a person's active legal capacity, when such need arises from the person's ability to understand and direct his or her actions", and that it will act only "according to domestic laws". Despite a significant reform to introduce supported decision-making and do away with guardianship, Ireland has not removed its reservations under Article 12.<sup>2</sup>

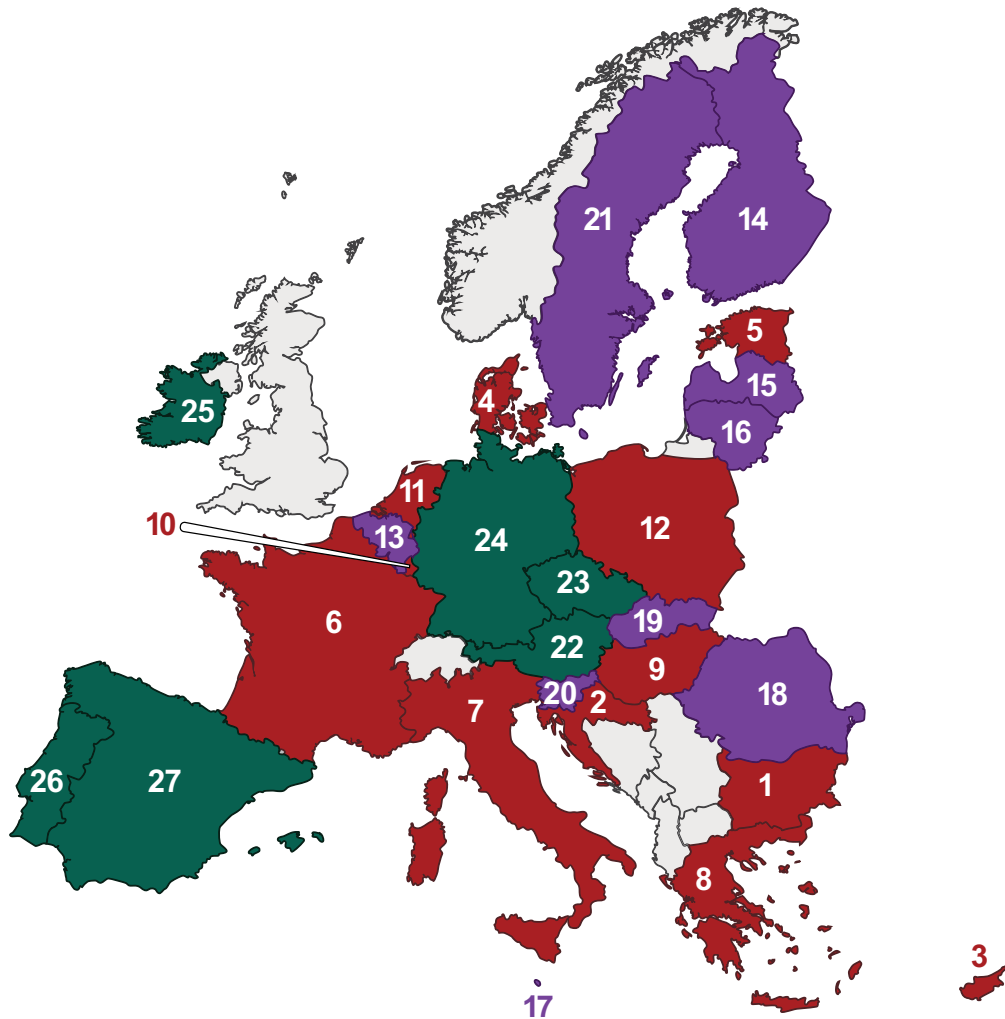
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1 EDF research. Regarding Ireland: <https://www.gov.ie/pdf/?file=https://assets.gov.ie/204199/b248d0f2-8fc4-43db-a92c-790718cca6ac.pdf#page=null>. Regarding Sweden: [https://www.international-guardianship.com/pdf/GBC/GBC\\_Sweden.pdf](https://www.international-guardianship.com/pdf/GBC/GBC_Sweden.pdf).

2 UN Treaty Collection, Convention on the Rights of Persons with Disabilities, entered into force 3 May 2008, [https://treaties.un.org/pages/ViewDetails.aspx?chapter=4&clang=en&mtdsg\\_no=IV-15&src=IND](https://treaties.un.org/pages/ViewDetails.aspx?chapter=4&clang=en&mtdsg_no=IV-15&src=IND).



## Legal Capacity Regimes in the European Union



**Full guardianship authorised:**

1. Bulgaria
2. Croatia
3. Cyprus
4. Denmark
5. Estonia
6. France
7. Italy
8. Greece
9. Hungary
10. Luxembourg
11. Netherlands
12. Poland

**Only partial guardianship and similar systems:**

13. Belgium
14. Finland
15. Latvia
16. Lithuania
17. Malta
18. Romania
19. Slovakia
20. Slovenia
21. Sweden

**Guardianship almost fully abolished:**

22. Austria
23. Czechia
24. Germany
25. Ireland
26. Portugal
27. Spain

There have been notable positive developments towards ensuring better protection of the rights of persons with disabilities. Six EU Member States have (almost) managed to fully abolish the deprivation of legal capacity of persons with disabilities in their law: **Austria, Czechia, Germany, Ireland, Portugal and Spain.**<sup>3</sup>

**Croatia** had abolished plenary guardianship of persons with disabilities in 2015.<sup>4</sup> However, in April 2023, the Constitutional Court declared a number of aspects of the Family Law unconstitutional, allowing again for full guardianship of persons with disabilities, as of 1 January 2024.<sup>5</sup> On 15 December 2023 the Croatian Parliament adopted an Act on Amendments to the Family Law (OG no. 156/23) reintroducing plenary guardianship.<sup>6</sup> All other 21 EU Member States retain stronger form of either full or partial guardianship.<sup>7</sup>

Significantly, all EU Member States which have abolished guardianship and shifted towards supported decision-making systems, nevertheless continue to allow for some forms of substitute decision-making, for example for certain types of decisions or in narrow circumstances, as described in more detail below.<sup>8</sup>

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3 See: DOTCOM, Recognition of legal capacity in EU Member States, <https://ec.europa.eu/social/main.jsp?catId=1542&langId=en>; and “The Vulnerable in Europe”, updated 5 July 2022, <https://www.the-vulnerable.eu/>; and Inclusion Europe, “Inclusion Indicators 2023: Union of equality? Here’s the reality”, <https://www.inclusion-europe.eu/inclusion-indicators-2023-union-of-equality-heres-the-reality/>.

4 Family Act, Official Gazette no. 103/15, entered into force 1 November 2015.

5 The law came into effect 1 January 2024. Constitutional Court of Croatia, decision on proposals for the initiation of the procedure for evaluating the compliance of the law with the Constitution Republic of Croatia, 18 April 2023.

6 The new law contains Article 234(4), as follows: “In exception to the Section 1 of this Article, if of exceptional importance for the protection of rights and interests of an adult person, the Court may fully deprive of legal capacity a person who is not able to establish any meaningful contact and express their will.”

7 Full guardianship is authorised in: Bulgaria, Croatia, Cyprus, Denmark, Estonia, France, Greece, Hungary, Italy, Luxembourg, Netherlands and Poland. Systems of partial guardianship, in some cases under different terminology, exist in: Belgium, Finland, Latvia, Lithuania, Malta, Romania, Slovakia, Slovenia and Sweden. See: DOTCOM, Recognition of legal capacity in EU Member States, <https://ec.europa.eu/social/main.jsp?catId=1542&langId=en>; and “The Vulnerable in Europe,” updated 5 July 2022, <https://www.the-vulnerable.eu/>; and Inclusion Europe, “Inclusion Indicators 2023: Union of equality? Here’s the reality”, <https://www.inclusion-europe.eu/inclusion-indicators-2023-union-of-equality-heres-the-reality/>; and ENNHRI and MHE, “Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs”.

8 As described below, this practice may have different terminology, depending on the Member State.

Any limits on legal capacity and on the rights of persons with disabilities to make decisions for themselves are incompatible with the CRPD which specifically prohibits the deprivation of legal capacity “in respect of a single decision”.<sup>9</sup>

Additionally, there is evidence that even under some systems of partial or limited deprivation of legal capacity, persons with disabilities are de facto unable to make any independent decisions once another person is in a role to make decisions on that individual’s behalf. As an example, in **Hungary**, an individual may be placed under full or partial guardianship, yet in practice, many persons subject to partial restriction of legal capacity have limited opportunity to act in relation to all decision-making areas.<sup>10</sup>

In other cases, courts continue to order more restrictive forms of substitute decision-making, even when less limiting and more supportive options are available, due to lack of information or insufficient resources in the community for supported decision-making to happen in practice.<sup>11</sup> In many countries, guardianship and deprivation of legal capacity continues to be a norm rather than an exception, such as **Belgium, Czechia, France, Hungary and Netherlands**.<sup>12</sup>

For example, **Czechia** has provided supported decision-making formally in law since 2014. However, a July 2023 report by the advisory body of the Ombudsman found that the country’s courts “still prefer restrictions of legal capacity to other forms of support”, resulting in “50 supported decision-making agreements approved by the courts each year, while at the same time up to 10 000 people are restricted in their legal capacity each year”.<sup>13</sup>

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9 CRPD Committee, General Comment No. 1, para. 27.

10 The decisive factor for being placed under guardianship is a medical assessment by court-appointed psychiatrists of the person’s “mental capacity”. CRPD Committee, “Inquiry Concerning Hungary under Article 6 of the Optional Protocol to the Convention”, 17 September 2020.

11 ENNHRI and MHE, “Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs”.

12 European Network on Independent Living (ENIL), “Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union”, February 2022, [https://enil.eu/wp-content/uploads/2022/03/ShadowReport\\_EU\\_Final\\_140222.pdf](https://enil.eu/wp-content/uploads/2022/03/ShadowReport_EU_Final_140222.pdf).

13 Ombudsman, Czech Ombudsman’s Advisory Body: Thousands of people with disabilities lack full legal capacity in violation with the UN Convention on the Rights of Persons with Disabilities”, 3 July 2023, [https://www.ochrance.cz/en/aktualne/czech\\_ombudsman\\_s\\_advisory\\_body\\_thousands\\_of\\_people\\_with\\_disabilities\\_lack\\_legal\\_capacity\\_despite\\_this\\_being\\_a\\_violation\\_of\\_the\\_un\\_convention\\_on\\_the\\_rights\\_of\\_persons\\_with\\_disabilities/](https://www.ochrance.cz/en/aktualne/czech_ombudsman_s_advisory_body_thousands_of_people_with_disabilities_lack_legal_capacity_despite_this_being_a_violation_of_the_un_convention_on_the_rights_of_persons_with_disabilities/).

Similarly, **Italy**<sup>14</sup> introduced the role of the support administrator, with the aim of protecting persons with disabilities – with the least possible limitation of capacity to act – in the execution of daily life functions through support interventions. However, incapacitation, which completely deprives the person of any capacity, still exists and is still applied.

In contrast to the persistence of substitute decision-making and deprivation of legal capacity among EU Member States, other countries, namely **Colombia, Costa Rica, Peru** and **Mexico**, have abolished guardianship and other forms of substitute decision-making *entirely* and guarantee the right to supported decision-making for adults with disabilities.<sup>15</sup>

## Development of supported decision-making systems

The development of supported decision-making systems in law and in practice in EU Member States is essential to enabling the exercise of legal capacity to many persons across the EU. This reflects a paradigm shift towards respecting the rights to autonomy and choice of persons with disabilities, which is an essential component of Member State's CRPD obligations. However, fewer than half of EU Member States have enshrined supported decision-making in law. The 13 countries that have supported decision-making in their laws are: **Austria, Belgium, Czechia, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Portugal, Spain** and **Sweden**.<sup>16</sup> In other countries, supported decision-making programmes may operate, even without legal guarantees to that form of support.<sup>17</sup>

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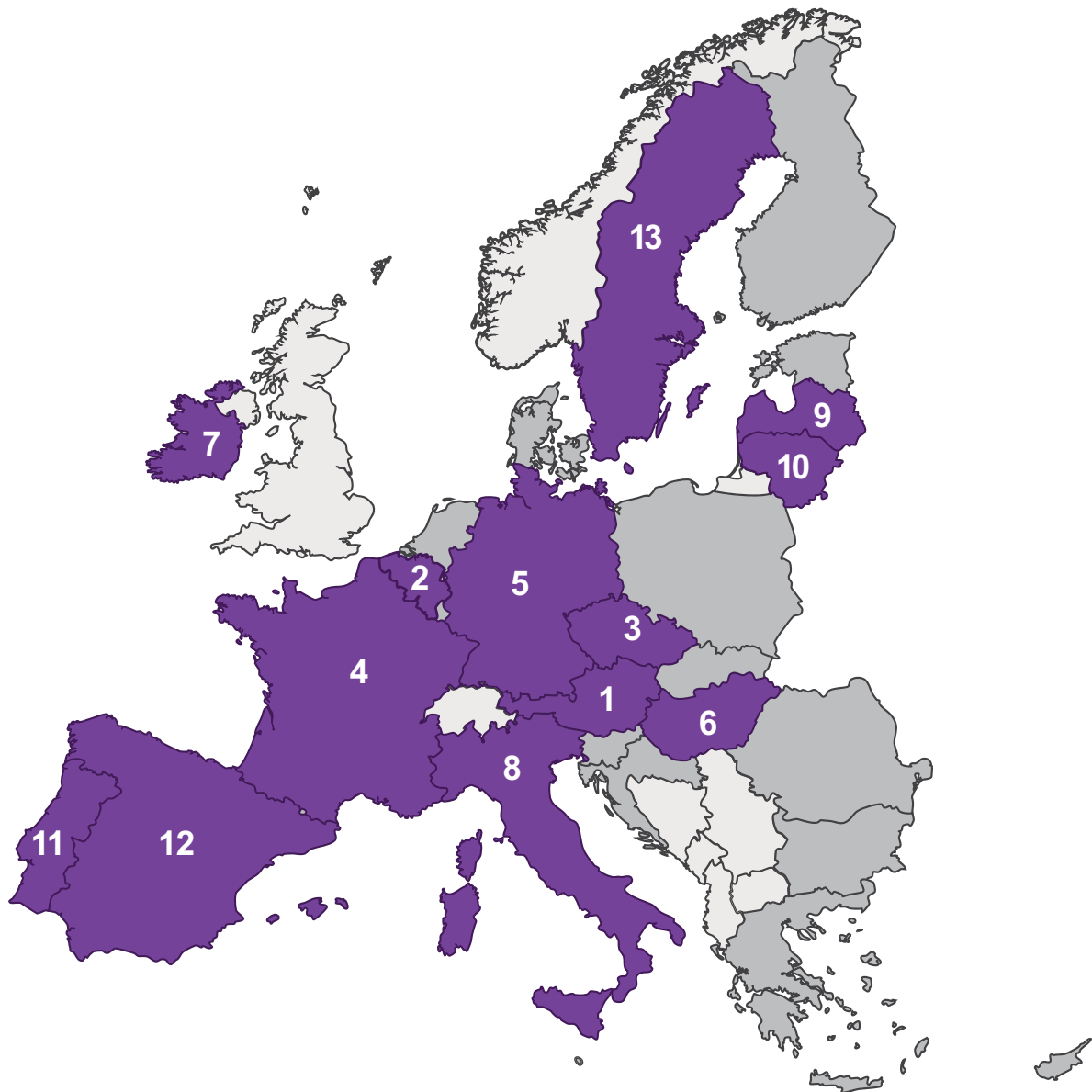
14 Italia Legge 6/2004, <https://www.parlamento.it/parlam/leggi/040061.htm>.

15 For example, in Mexico, in April 2023, Congress passed a new national civil and family procedure code which eliminated guardianship and grants everyone over 18 full legal capacity and the right to supported decision-making. Individual states must revise state laws in order to implement the new law. Human Rights Watch, "Mexico: States' Inaction on Legal Capacity", 18 May 2023, <https://www.hrw.org/news/2023/05/18/mexico-states-inaction-legal-capacity>; and Constantino Caycho R.A., Bregaglio Lazarte R.A., "A Four-Speed Reform: A Typology for Legal Capacity Reforms in Latin American Countries", *Laws*, 2023, 12(3):45, <https://doi.org/10.3390/laws12030045>.

16 As of March 2022. EDF research. No information regarding Luxembourg was identified in the research.

17 For details, see: ENNHRI and MHE, "Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs".

## Supported Decision-making Systems in the European Union



**Countries with supported decisions-making systems established by law:**

- |            |               |              |
|------------|---------------|--------------|
| 1. Austria | 6. Hungary    | 11. Portugal |
| 2. Belgium | 7. Ireland    | 12. Spain    |
| 3. Czechia | 8. Italy      | 13. Sweden   |
| 4. France  | 9. Latvia     |              |
| 5. Germany | 10. Lithuania |              |

Organisations of persons with disabilities, NGOs and other local and national actors are also actively involved in the implementation of supported decision-making in EU Member States.

This section outlines a few examples supported decision-making systems adopted more recently in EU Member States.<sup>18</sup>



## Ireland

Ireland's Assisted Decision-Making (Capacity) Act 2015, which came into effect in April 2023, presumes legal capacity and has three tiers of support. The first, assisted decision-making, allows for a person to appoint an assistant or more than one person to provide information, explain relevant information and considerations relating to a decision, to assist with taking and implementing the decision, all while understanding the individual's will and preferences. They sign a decision-making assistance agreement.<sup>19</sup> A co-decision-making agreement involves a person with a disability identifying a person to make joint decisions, whose roles and responsibilities are consistent with those under assisted decision-making, but any relevant decisions are made jointly. The supporter must "acquiesce with the wishes of the appointer in respect of the relevant decision".<sup>20</sup> The law also "allows for the appointment of a decision-making representative [or more than one person] to take specified decisions on behalf of a person and for the taking of certain decisions by a court on behalf of a person in limited circumstances".<sup>21</sup> In this case, a person nevertheless loses the right to legal capacity.

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18 For more examples, see ENNHRI and MHE, "Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs"; and European Association of Service providers for Persons with Disabilities (EASPD), "Models on innovative practices focusing on supported decision-making mechanisms", December 2021, <https://easpd.eu/resources-detail/models-on-innovative-practices-focusing-on-supported-decision-making-mechanisms/>.

19 Assisted Decision-Making (Capacity) Act 2015, part 3, Assisted Decision-Making.

20 Assisted Decision-Making (Capacity) Act 2015, part 4, Co-Decision-Making.

21 "Initial Report of Ireland Under the Convention on the Rights of Persons with Disabilities", 8 November 2021, [https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FIRL%2F1&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FIRL%2F1&Lang=en); and Assisted Decision-Making (Capacity) Act 2015, chapter 4.



## Portugal

A new supported decision-making regime, called *acompanhamento* – or accompaniment or support –, came into force in Portugal in 2019.

While abolishing the previous system that involved total or near total loss of capacity by an individual, the new system is not compliant with the CRPD. A person with a disability chooses an assistant (or assistants) and a court determines the activities in which the supporter will assist the person. However, powers of representation may be granted by the court to the custodian. The court also has the authority to limit certain rights of the person under *acompanhamento*, such as to marry or to write a will. The requirements for revising the agreement are cumbersome and involve applying to the court again, with the court ultimately deciding about modifications or termination. There are also options for third parties to intervene in the *acompanhamento* process at different points.<sup>22</sup>



## Spain

In Spain, a 2021 legal reform instituted a supported decision-making system based on respect for the will and preferences of the individual with disabilities and abolished legal incapacitation and guardianship. This system is available to anyone who requests support. This can be a person with a disability but also someone who does not have a formally recognised disability (for example an older person).

The law envisions four different types of support: those of a voluntary nature, *de facto* guardianship, curatorship and judicial defender. Support measures of a “voluntary nature” are established by the person with disabilities who designates the supporter and the extent of support and they are recorded in a public deed.

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22 EASPD, “Models on innovative practices focusing on supported decision-making mechanisms”, December 2021; and “The Vulnerable in Europe: Portugal”, 5 July 2022, <https://www.the-vulnerable.eu/Questions.aspx?c=pt#>.

The law also recognises a *de facto* support mechanism (known as guardianship). The guardian should provide sufficient support and must have a formal authorisation any time they represent or act on behalf of a person with disabilities. The person with disabilities can dismiss this supporter and change forms of supported decision-making at any time.<sup>23</sup>

A court may also appoint a curator, or more than one, who is required to provide supported decision-making. Curators are also authorised by the court to take certain decisions on behalf of the individual with disabilities in exceptional circumstances. Persons with disabilities can decide who can and who cannot be a curator for them. The curator will assist the person to whom they provide support “in the exercise of their legal capacity, respecting their will, wishes and preferences; ensure that the person with disabilities can develop their own decision-making process; and seek to foster the abilities of the person they are supporting so that they can exercise their ability with less support in the future”.<sup>24</sup> This aspect of the law allows for substitute decision-making, and thus for the deprivation of legal capacity.

The new law also allows courts to appoint a judicial defender for some specific situations, such as when the curator cannot perform their duties for a certain period; there is a change in curator, until the new curator is established; there is a conflict of interest between the support figure and the person with disabilities; or there is circumstantial impossibility for the usual support figure to exercise their support. The person with disabilities is heard by the court in the process of appointing a judicial defender.<sup>25</sup>

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23 De Salas Murillo S., “The New Support System for the Exercise of Legal Capacity in Spanish Law 8/2021, of June 2: A General Overview, Questions, and Challenges”, *Actualidad Jurídica Iberoamericana*, N° 17, June 2022, ISSN: 2386-4567, pp. 16-47, <https://revista-aji.com/wp-content/uploads/2022/09/01.-Sofia-de-Salas-pp.-16-47.pdf>.

24 Law 8/2021, Chapter 4, Curatorship.

25 Law 8/2021, Chapter 5, Judicial Defender.



In Catalonia, reforms in 2010 established an assistance mechanism which allows for supported decision-making requested and directed by persons with disabilities in the areas of life that they specify. Support can be provided by an individual or an organisation.<sup>26</sup> In 2021, further reforms determined that assistance service is the core mechanism of support which replaces and abolishes not only full guardianship, consistent with the state reform, but also partial guardianship known as curatorship (see above).<sup>27</sup> The organisation Support-Girona has provided support to the majority of individuals utilising this mechanism. The government finances the services and assistants are subject to public control and supervised by the court authority on a yearly basis.<sup>28</sup>



## Greece

Following the recommendations of the CRPD Committee, the Ministry of Justice of Greece established a Working Group to examine the revision of the current guardianship scheme and the adoption of the legal scheme of supported decision-making. The national confederation of persons with disabilities (NCDP) has a representative in this working group. There were a few meetings during the first half of 2023, but the members of the Working Group have not met since the national elections in the summer of 2023. During the first meetings, the task of the Group was to find good practices from other EU countries.

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26 ENNHRI and MHE, “Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs”, <https://supportgirona.cat/en/serveis/suport-juridic-i-social>.

27 Support-Girona, “Legal and Social Support”, <https://supportgirona.cat/en/serveis/suport-juridic-i-social>.

28 ENNHRI and MHE, “Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs”, <https://supportgirona.cat/en/serveis/suport-juridic-i-social>.



## Powers of representation

Most countries also provide for power of representation arrangements that allow individuals to express their will and preferences, including the selection of an individual to make decisions on their behalf, at a time when they may not be in a position to communicate them. Advance plans may also prove particularly useful for persons who may be distressed, who experience psychosis or dementia, so that third parties – including medical staff and others – can understand the person’s will and preferences and not make decisions on their behalf.<sup>29</sup> These can take the form of private mandates, advance directives, powers of attorney, or the voluntary designation of a representative. In **Germany**, advance directives are binding under law, including in the context of mental health care. The law also specifies that, if the person does not have an advance directive, their presumed will and preferences concerning treatment must be determined based on specific evidence such as previous oral statements.<sup>30</sup>

National law provides for the possibility for vulnerable adults to set up their future protection via private mandates in 16 Member States: **Austria, Belgium, Croatia, Czechia, Denmark, Finland, France, Germany, Hungary, Ireland, Lithuania, Malta, Portugal, Romania, Spain and Sweden.**<sup>31</sup>

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29 WHO, “Supported decision-making and advance planning. WHO QualityRights Specialized training”.

30 WHO, “Legal Capacity and the Right to Decide. WHO QualityRights Core training: mental health and social services”, 2019, <https://apps.who.int/iris/handle/10665/329539>.

31 European Commission, “Study on the cross-border legal protection of vulnerable adults in the EU”, November 2021, page 68, <https://op.europa.eu/en/publication-detail/-/publication/facf667c-99d6-11ec-83e1-01aa75ed71a1/language-en>.

In the **Netherlands**, the law provides the possibility to establish powers of representation by private mandate; but it does not recognise a lasting power of attorney for specific situations involving loss of legal capacity and vulnerable adults.

In **Poland**, the only legal solution that can be used as a private mandate is a general power of attorney, which is not designed specifically to protect the interests of vulnerable adults, but may be used to that end.

9 EU Member States – **Bulgaria, Cyprus, Estonia, Greece, Italy, Latvia, Luxembourg, Slovakia** and **Slovenia** – do not have provisions on powers of representation, meaning that people cannot decide in advance to give to someone the power to represent or act for them (for example to sign a contract or to take a decision if they are in a coma).<sup>32</sup>

## Supported decision-making and continuing restriction of legal capacity

Unfortunately, across all EU Member States, legal guarantees of supported decision-making and/or the existence of supported decision-making systems are not sufficient guarantees for the exercise of legal capacity of all persons with disabilities. All EU Member States retain some form, even if very limited, of substitute decision-making.

Even where well-crafted supported decision-making systems exist that envisage substitute decision-making as a last resort, through court-appointed representatives with appropriate safeguards, allowable only in a limited set of circumstances, the existence of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not consistent with the CRPD.<sup>33</sup>

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32 Ibid, page 70.

33 CRPD Committee, General Comment No. 1, paras. 27 and 28.

The examples of supported decision-making above note the aspects of the systems which allow for substitute decision-making. Additional examples are provided here.

Regarding **France**, the CRPD Committee criticised the government for laws that deprive persons of their legal capacity and autonomy through guardianship and wardship, on the basis of medical assessments of the person's mental capacity and "the absence of supported decision-making mechanisms compatible with the Convention."<sup>34</sup>

**Austria** has almost managed to abolish the full deprivation of legal capacity. However, there is a lack of supported decision-making offers and services in all regions. So, the new law – which is, in principle, a good law – is not properly implemented across the Austrian regions (Länder) that would be responsible for offering services for supported decision-making. As a result, the judges are often forced to call for a representation (for single matters only) because of a lack of alternatives, even if a person would be able to make their own decisions with the proper support. This has been criticised by the CRPD Committee in its last concluding observations on Austria.

**Germany** replaced its nearly 100-year-old guardianship law in 1992 with a custodianship law (Betreuungsgesetz), which has since been reformed twice. Under the reformed law, which came into effect on 1 January 2023, persons with disabilities cannot be formally deprived of their legal capacity. However, courts can still appoint a legal guardian (legal custodian) for a person with a disability if the person concerned "cannot manage their affairs due to illness or disability". The custodianship court can determine the area of the responsibility of the legal custodian unless the person under custodianship is a person with "free will". But even if the person does not have "free will", the court cannot appoint a custodian if "other assistance" is available. The custodianship authority (established under the reformed law) can be asked to recommend such assistance as a form of support, making the appointment of a legal custodian

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34 CRPD Committee, "Concluding observations on the initial report of France", 4 October 2021, [https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FFRA%2FCO%2F1&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FFRA%2FCO%2F1&Lang=en).

unnecessary. However, the authority is not entitled to determine, select and impose such “other assistance.” “Other assistance” is itself a vague legal term requiring interpretation based on good examples of supported decision-making. Such examples have not been identified. This is the weak point of the reformed law and one of the reasons that the CRPD Committee came to the conclusion that the reformed guardianship law still does not eliminate all forms of substitute decision-making and, therefore, is not in line with Article 12.<sup>35</sup>

The CRPD Committee has found that in **Hungary** “attributes of a substitute decision-making regime have been retained in the supported decision-making mechanism”, resulting in a measure that is “ineffective and discriminatory.”<sup>36</sup> The supported decision-making regime is available only to persons who have a “minor decrease” in their “mental capacity”. Persons under this regime are restricted in the exercise of certain rights, such as parental rights, and are excluded from holding certain public positions. One supporter may provide assistance to up to 45 persons in some cases and the system is not well known among persons with disabilities and legal practitioners. Other forms of support for exercising legal capacity are not officially available to persons with disabilities.<sup>37</sup>

**Sweden** revised its legal capacity law in 1989. The current law and practice include both substitute decision-making (administrator) and some possibilities, although weaker, for supported decision-making (“good man”). In 1989 persons who had previously been declared “legally incapacitated” got an administrator. A Swedish court may appoint an administrator to make decisions on behalf of a person with a disability without their consent. Such an appointment is limited to cases necessary to prevent represented persons from

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35 CRPD Committee, “Concluding observations on the combined second and third periodic report of Germany”, 9 September 2023.

36 CRPD Committee, “Concluding observations on the combined second and third periodic report of Hungary”, 22 May 2022, [https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FFRA%2FCO%2F1&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FFRA%2FCO%2F1&Lang=en).

37 CRPD Committee, “Inquiry Concerning Hungary under Article 6 of the Optional Protocol to the Convention”, 17 September 2020.

taking “legal actions that might harm their own interests”.<sup>38</sup> The person represented is fully deprived of their legal capacity in the specific situations covered by the court decision.<sup>39</sup>

Under the less restrictive form for decision-making, a person, known as “good man”, could be a form of supported decision-making. A good man should only act with the consent of the person with a disability, who also *de jure* retains their legal capacity. Nevertheless, the system has been criticised, as the mentor is expected to act in the “best interests” of the person with disabilities. The good man does not have an obligation to obtain their will and preferences, and can take legal and other decisions on their behalf, when a person “does not understand the matter”, implying an assessment of “the ability to consent”, a concept inconsistent with the right to legal capacity and not acknowledged by the CRPD.<sup>40</sup> In addition to what is provided by law, Sweden developed a voluntary, not legally binding support programme in municipalities with a limited scope, called “personal ombud”. The good man, when voluntary, and the personal ombud may contribute to self-determination and be considered forms of support for decision-making. Appointed administrators and a good man without consent are forms of limiting legal capacity, constituting substitute decision-making.

The Swedish Disability Rights Federation reported that over the last eight years there has been an increase in the number of nomination of administrators, and thus people deprived of their legal capacity. The Council of Legislation has expressed concerns regarding the risk that restrictive decisions could be made on grounds too weak.<sup>41</sup> In addition, in March 2024, the CRPD Committee

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38 However, the administrator cannot legally take certain kinds of legal actions, such as voting, consent to medical treatment or marriage, or signing a will. An individual retains their right to decisions in those cases.

39 Fridström Montoya T., “Supported Decision-Making in Swedish Law Is the »Good Man« a Good or Bad Guy in Light of the CRPD?” *Psychiatrie Verlag GmbH*, 2019, Köln, <https://psychiatrie-verlag.de/wp-content/uploads/2019/01/919-Fridstr%C3%B6m-Montoya-English-version.pdf>. See also: Odlöv T., “Reply to questionnaire for the country reports – Sweden,” 4th World Congress on Adult Guardianship, [https://www.international-guardianship.com/pdf/GBC/GBC\\_Sweden.pdf](https://www.international-guardianship.com/pdf/GBC/GBC_Sweden.pdf).

40 Ibid.

41 Second Alternative report on the implementation of the UN Convention on the Rights of Persons with Disabilities in Sweden, Joint Civil Society report submitted by the Swedish Disability Rights Federation for the 30th CRPD committee session, March 2024.

continued to raise concerns about the lack of measures taken by the Swedish government to replace substitute decision-making regimes with supported decision-making mechanisms, as well as about insufficient training on supported decision-making, the lack of nationally consistent application and the unequal access across municipalities to the support provided by the “Personal Ombud” programme.<sup>42</sup>

Similarly, when it comes to court decisions, a study on the legal capacity court cases in **Portugal**, analysing 752 sentences (including only people aged between 18 and 55) in three selected courts, reveals a strong predominance of the more restrictive measures of accompaniment. Between 2019 and 2022, in 82% of the sentences accompanying persons were granted general powers of representation, contrary to the recommendations of the CRPD. In the most recent judgments, handed down between February 2022 and February 2023, this situation changed only slightly: 78% of judgments granted powers of general representation to accompanying persons, and 21% resulted in special representation, i.e. a less restrictive accompanying measure in terms of rights.

Finally, it was reported to EDF that in **Italy** the role of support administrator, who should support the person in making their decisions, currently fails in practice. This is due to lack of training of support persons and service providers, shortage of staff, and persistence of stereotypes and prejudices that still influence the actions of operators with respect to disability.<sup>43</sup>

EDF was also told that it is sometimes residential care providers, hospitals, or social security institutions and/or professionals such as doctors or banks, who require substitute decision-making even for very simple operations such as dental care and/or administrative operations.

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42 CRPD Committee, “Concluding observations on the combined second and third periodic reports of Sweden”, para. 27.

43 On 6 July 2023 the First Chamber of the European Court of Human Rights recognised a violation of the European Convention of Human Rights (ECHR) in the case *Calvi and C.G. v Italy* concerning legal protection measure imposed on an older person and placement in nursing home in social isolation for three years.

## The role of the European Union

As Party to the CRPD, the EU has the obligation to implement the Convention within its scope of competence. Because laws on legal capacity are under the competence of the Member States, it cannot impose a full reform of the legal capacity regimes across the Union but could take measures to promote reforms of legal capacity regimes and support the development of supported decision-making systems.

In 2015, the CRPD Committee recommended that the EU take measures to ensure that all persons with disabilities who have been deprived of their legal capacity can exercise their rights provided in the EU treaty and legislation. The Committee also recommended to step up efforts to foster research, data collection and exchange of good practices on supported decision-making, in consultation with representative organisations of persons with disabilities.<sup>44</sup>

Despite these recommendations and the adoption of the Strategy on the rights of persons with disabilities 2021-2030, the EU has yet to develop concrete actions to protect the exercise of legal capacity by persons with disabilities, as well as their choice and autonomy.<sup>45</sup>

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44 CRPD Committee, “Concluding observations on the initial report of the European Union”, 2 October 2015.

45 EDF, “Alternative report for the second review of the EU by the CRPD Committee”, February 2022.





## Cross-border protection of adults

In May 2023, the European Commission proposed a controversial legislation on the “cross-border protection of adults”<sup>46</sup> which contravenes the CRPD. The proposed law would regulate the situation of adults, mostly persons with disabilities and older adults, who are deemed “not in a position to protect their own interest” and who are in a cross-border situation.<sup>47</sup> Under the proposed text, Member States would have to recognise measures of deprivation of legal capacity, as well as measures of placement, taken by another EU Member State. This proposal has been highly criticised by the disability movement,<sup>48</sup> organisations representing older persons,<sup>49</sup> as well as by the UN Special Rapporteur on the Rights of Persons with Disabilities and the UN Independent Expert on Older Persons.<sup>50</sup> It comes from a push by the European Commission to promote the ratification of the 2000 Hague Convention on the International Protocol of Adults,<sup>51</sup> an international convention also denounced as not fully compliant with the CRPD by the UN experts and the disability movement.<sup>52</sup>

46 [https://ec.europa.eu/commission/presscorner/detail/en/ip\\_23\\_2955](https://ec.europa.eu/commission/presscorner/detail/en/ip_23_2955)

47 These can be people that have assets or estates in another country, who are seeking medical care abroad, or who relocate in another EU Member State.

48 EDF, “The proposed Regulation on Protection of Adults must be amended”, 6 November 2011, <https://www.edf-feph.org/the-proposed-regulation-on-protection-of-vulnerable-adults-must-be-amended/>.

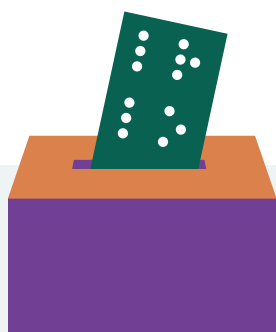
49 Feedback to the legislative proposal by AGE Platform Europe, 18 August 2023, [https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12965-Civil-judicial-cooperation-EU-wide-protection-for-vulnerable-adults/F3434594\\_en](https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12965-Civil-judicial-cooperation-EU-wide-protection-for-vulnerable-adults/F3434594_en).

50 Joint Submission by the UN Special Rapporteur on the rights of persons with disabilities (Gerard Quinn) and the Independent Expert on the enjoyment of all human rights by older persons (Claudia Mahler), 2 August 2023.

51 Convention of 13 January 2000 on the International Protection of Adults.

52 EDF, “New study and UN Statement on the Hague Convention on the protection of adults”, 14 July 2021, <https://www.edf-feph.org/new-study-and-un-statement-on-the-hague-convention-on-the-protection-of-adults/>.

At the time of the publication of this report, the proposed regulation is being discussed by the EU Institutions. If the text is changed to only accept support to make decision, the regulation would be useful to promote the recognition and development of supported decision-making systems across Europe. On the contrary, if substitute decision-making is covered and must be recognised by Member States, even those who have reformed their laws, the regulation risks to crystallise denial of legal capacity at a large scale in Europe.



## Political Participation

Another area in which the EU could guarantee the legal capacity of persons with disabilities, within its competence, is political participation.

By revising the European Electoral Law, the EU could ensure that all persons with disabilities have the right to vote and stand for election during the European elections, irrespective to whether they are denied these rights in the national elections. This has been a demand and campaign of EDF for many years.

## Summary

- Some EU countries have made efforts to move to supported decision-making systems, with varying success.
- However, these systems still retain forms of substitute decision-making and, in general, do not ensure the right to legal capacity.
- Even in cases where the text of the law is compliant with the CRPD, lack of resources, training and enforcement mean that persons with disabilities are still being deprived of legal capacity.
- While the EU does not have full competency to act on legal capacity in Member States, current efforts to uniformise cross-border protection are potentially damaging to the right of legal capacity.

[Back to Contents](#)

## Chapter 4:

# Denial of legal capacity and human rights violations in Europe



As a result of the continued use of substitute decision-making across Europe, human rights abuses against persons with disabilities persist, both in relation to violations of the right to legal capacity and others. This chapter looks at three specific areas in connection to the denial of legal capacity: forced treatment and placement, violations of sexual and reproductive rights, and institutionalisation. In addition to Article 12 of the CRPD, these practices result in numerous other violations of the Convention, regarding the rights to non-discrimination, liberty and security of person, access to justice, private and family life, live independently in the community, health, the right to be free from inhuman and degrading treatment, and the rights of women with disabilities – among others.

The European Court of Human Rights (ECtHR) has issued several important rulings regarding violations of the human rights of persons with disabilities in EU Member States, including regarding legal capacity, institutionalisation and forced sterilisation, as described below. It is not within the scope of this report to analyse the Court's overall approach. Scholars have found that the ECtHR recognises the need to protect persons with disabilities from discriminatory treatment and the obligation to involve people with intellectual disabilities in decisions.<sup>1</sup> However, the ECtHR diverges from the CRPD in recognising the right to legal capacity in all circumstances, but instead requires lawfulness, safeguards, and a tailor-made, individual response from states when depriving individuals of their legal capacity.<sup>2</sup> It has not prohibited guardianship

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- 1 For example: **Cojocariu C.**, "A.M.V. v. Finland: Independent Living, A Bridge Too Far for the European Court of Human Rights", *Strasbourg Observers*, 10 May 2017, <https://strasbourgobservers.com/2017/05/10/a-m-v-v-finland-independent-living-a-bridge-too-far-for-the-european-court-of-human-rights/>.
  - 2 In *N. v Romania*, the ECtHR found a violation of the right to private life in the manner in which N. had been deprived of his legal capacity. Nevertheless, it acknowledged that the "incapacitation proceedings concerning the applicant had a legal basis" and that the [deprivation of his legal capacity] was taken in the applicant's interests, to protect his health as well as the rights and freedoms of others. *N. v Romania*, application no. 38048/18, 16 November 2022. **Blomme N.**, "N. v. Romania (No. 2): 'To Be or Not to Be?' – Applying Article 8 or Article 14 ECHR in Mental-Health Cases," *Strasbourg Observers*, 25 April 2022, <https://strasbourgobservers.com/2022/04/25/n-v-romania-no-2-to-be-or-not-to-be-applying-article-8-or-article-14-echr-in-mental-health-cases/>. See also: **Constantin Cojocariu C.**, "A.M.V. v. Finland: Independent Living, A Bridge Too Far for the European Court of Human Rights".

regimes or forced placement.<sup>3</sup> The Court has ruled that “forced medication of a mentally ill patient may be justified, in order to protect the patient and for the protection of others”.<sup>4</sup>



## Gender perspective

There are a few resources that explore how people are affected by the deprivation of their legal capacity because of their gender and other characteristics. However, ad hoc studies and surveys show that women with disabilities can face higher risks and occurrences of deprivation of their legal capacity and coercion.

For example, in Ireland, participants in a 2021 consultation regarding Ireland’s compliance with the CRPD felt that there can be gender biases in the diagnosis of mental health, personality and psychosocial disorders, with more women diagnosed than men.

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- 3 For example: ECtHR, *DD v Lithuania*, no. 13469/06, 14 February 2012. The Court found that D.D.’s deprivation of liberty was lawful under the circumstances because it was supported by a medical report that showed the applicant suffered from “a chronic mental illness” and a social worker’s report that said she could not live on her own. Nelson L., “Stanev v. Bulgaria: The Grand Chamber’s Cautionary Approach to Expanding Protection of the Rights of Persons with Psychosocial Disabilities,” *Strasbourg Observers*, 29 February 2012, <https://strasbourgobservers.com/2012/02/29/stanev-v-bulgaria-the-grand-chambers-cautionary-approach-to-expanding-protection-of-the-rights-of-persons-with-psycho-social-disabilities/>. See also: Ferri D., Broderick A., “The European Court of Human Rights and the Human Rights Model of Disability: Convergence, Fragmentation and Future Perspectives”, in Czech P., Heschl L., Lukas K., Nowak M. and Oberleitner G. (eds.), *European Yearbook on Human Rights*, 2019 (Intersentia), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=4011395](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4011395).
  - 4 ECtHR, “Guide on Article 8 of the European Convention on Human Rights Right to respect for private and family life”, updated 30 April 2018, <https://fln.dk/-/media/FLN/Publikationer-og-notater/EMRK/Guide-on-Article-8-of-the-European-Convention-on-Human-Rights.pdf?la=da&hash=9A53A909656A705FFE4CFF499EC5862343A9B2AA>.

As a result, women experience higher rates of forced treatment and electroconvulsive therapy.<sup>5</sup>

In the United Kingdom, research showed that Black and minority ethnic women were three to six times more likely to be admitted to mental health units than average and more likely to be forcibly admitted.

On the other hand, they were less likely to be admitted to women's crisis houses and less likely to be referred to talking therapies.<sup>6</sup>

In Spain, the organisation CERMI Women's Foundation reported to EDF cases of women being deprived of their legal capacity and being institutionalised in psychiatry at the request of their male partner, which is a form of control and gender-based violence.

Women and girls with disabilities are also at higher risks of forced sterilisation and forced contraception than men and boys with disabilities. This topic is explored in the section below.

## Forced treatment and placement

Despite supported decision-making and progress in moving away from guardianship in a number of countries, coercive measures in health and mental health settings remain prevalent in Europe. Mental health laws across the EU allow for medical actions to be taken without the free and informed consent of a person with a disability, in violation of their legal capacity and other rights.<sup>7</sup>

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- 5 Centre for Effective Services, "Ireland's Draft State Report under the United Nations Convention on the Rights of Persons with Disabilities Report from Public and Stakeholder Consultations", May 2021, <https://www.gov.ie/pdf/?file=https://assets.gov.ie/204200/2f5ad4a7-d406-42ea-9cf1-c0ad86bb8605.pdf#page=null>.
  - 6 Kalathil J., "Recovery and Resilience: African, African Caribbean and South Asian Women's Stories of Recovering from Mental Distress", Mental Health Foundation and Survivor Research, 2011, [https://www.academia.edu/3297598/Recovery\\_and\\_Resilience\\_African\\_African\\_Caribbean\\_and\\_South\\_Asian\\_Womens\\_Stories\\_of\\_Recovering\\_from\\_Mental\\_Distress](https://www.academia.edu/3297598/Recovery_and_Resilience_African_African_Caribbean_and_South_Asian_Womens_Stories_of_Recovering_from_Mental_Distress).
  - 7 European Union Agency for Fundamental Rights (FRA), "From Institutions to Community-based Living: Perspectives from the Ground", 2018, [https://fra.europa.eu/sites/default/files/fra\\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\\_en.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives_en.pdf).

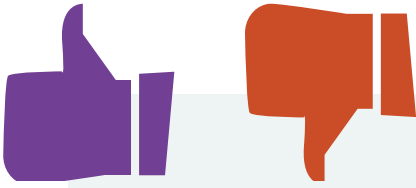
The Parliamentary Assembly of the Council of Europe has found that “all Council of Europe member states provide for involuntary placement and treatment, mostly through specific mental health laws”,<sup>8</sup> and that involuntary placement and involuntary treatment procedures give rise to a large number of human rights violations.<sup>9</sup> It also noted that in Europe “there is an overall increase in the use of involuntary measures in mental health settings”, in contradiction to human rights standards.<sup>10</sup> The Council of Europe’s Human Rights Commissioner, Dunja Mijatović, has described mental health systems, as “a longstanding source of human rights violations”.<sup>11</sup>

The CRPD Committee has criticised states for mental health and other laws that permit the involuntary psychiatric treatment of persons with psychosocial disabilities, the deprivation of liberty on grounds of disability and perceived dangerousness, and the use of physical restraints and solitary confinement, even in states that have supported decision-making in place.<sup>12</sup>

Forced treatment and placement can have long-lasting and sometimes irreversible consequences for the persons affected. In some cases, it leads to torture, ill-treatment, overmedication and/or the death of the person. Many survivors of involuntary treatment report a complete loss of trust in the health care system.<sup>13</sup>

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- 8 Parliamentary Assembly of the Council of Europe (PACE), “Ending coercion in mental health: the need for a human-rights based approach”, Doc. 14895, May 2019, <https://pace.coe.int/pdf/c9ff42fa77c73dc5ba11a9331283d60e6a62c227b149ca6ffb2c709dfc1172a7/doc.%2014895.pdf>.
  - 9 PACE, “The case against a Council of Europe legal instrument on involuntary measures in psychiatry,” Recommendation 2091, 2016, <https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-EN.asp?fileid=22757>.
  - 10 Emphasis added. PACE, “Ending coercion in mental health: the need for a human-rights based approach”, May 2019.
  - 11 Council of Europe Commissioner for Human Rights, “Reform of mental health systems: an urgent need and a human rights imperative”, Human Rights Comment, 7 April 2021, <https://www.coe.int/en/web/commissioner/-/reform-of-mental-health-services-an-urgent-need-and-a-human-rights-imperative>.
  - 12 Examples from recent years include: CRPD Committee, “Concluding observations on the initial report of France”, 4 October 2021; and CRPD Committee, “Concluding observations on the combined second and third periodic report of Hungary”, 22 May 2022; and CRPD Committee, “Concluding observations on the combined second and third periodic reports of Spain”, 13 May 2019.
  - 13 FRA, “Involuntary placement and involuntary treatment of persons with mental health problems”, 2012, [https://fra.europa.eu/sites/default/files/involuntary-placement-and-involuntary-treatment-of-persons-with-mental-health-problems\\_en.pdf](https://fra.europa.eu/sites/default/files/involuntary-placement-and-involuntary-treatment-of-persons-with-mental-health-problems_en.pdf); and Mental Health Europe, “Compulsory psychiatric treatment and its alternatives – the facts”, 2015, <https://www.mhe-sme.org/compulsory-psychiatric-treatment-and-its-alternatives-the-facts/>.





## Positive and negative examples from the European Court of Human Rights

The ECtHR found violations of the European Convention on Human Rights in relation to forced medical treatment. It has held that an individual's right to refuse medical treatment and that a medical intervention in defiance of the subject's wishes will give rise to an interference with respect to private life and in particular the right to physical integrity, although calls for appropriate "safeguards" rather than an outright prohibition.<sup>14</sup>

For example, in the case of *X v. Finland*, the Court found a violation of the right to private life with the forced administration of medication of an individual with a psychosocial disability, who had also been subject to forced hospitalisation. The Court called the involuntary treatment "a serious interference with a person's physical integrity". The Court highlighted the automatic authorisation for forcible administration of medication if *X* refused the treatment and that decision-making was solely in the hands of the doctors, who could take even quite radical measures irrespective of *X*'s will and preferences. While significant, the Court also highlighted that the absence of safeguards regulating forced medication gave rise to the human rights violation.<sup>15</sup> (See also cases related to forced sterilisation and abortion, below.)

Relatedly, the ECtHR has found forced treatment of persons with disabilities "who are entirely incapable of deciding for themselves"<sup>16</sup> permissible, including as related to presumed "dangerousness", as long as they are carried out with "clear legal guidelines and with the

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14 ECtHR, "Guide on Article 8 of the European Convention on Human Rights Right to respect for private and family life".

15 The decision also found that "the appointment of a guardian for the applicant, albeit against her will, was not in contravention of the requirements of a fair trial." ECtHR, *X v. Finland*, application no. 34806/04, 3 July 2012.

16 ECtHR, *G.M. and Others v. the Republic of Moldova*, application no. 44394/15, 22 November 2023.

possibility of judicial review”.<sup>17</sup> This is however not something that is acceptable under the CRPD.

The interpretation of the European Convention on Human Rights, which was adopted in 1950, should not violate the rights of persons with disabilities. A provision under its Article 5 on the right to liberty and security is particularly problematic because it authorises “the lawful detention of (...) persons of unsound mind”.<sup>18</sup> Concerns were also raised about national courts following jurisprudence from the ECtHR despite them not being fully aligned with the CRPD.

## The Council of Europe’s draft additional protocol to the Oviedo Convention

Since 2013, the Council of Europe’s Steering Committee on Bioethics (formerly Committee on Bioethics – DH-BIO) has been in the process of drafting an additional protocol to the Oviedo Convention on Bioethics, which seeks to regulate the use of involuntary placement and involuntary treatment of people with psychosocial and other disabilities in Council of Europe member states, rather than eliminating these practices. It maintains an approach to mental health policy and practice that is based on coercion, which is incompatible with the CRPD. In addition to allowing for continued coercive measures of involuntary treatment, placement and institutionalisation, the additional protocol would create a legal conflict for all Council of Europe member states as they have all ratified the CRPD.<sup>19</sup>

The initiative has been criticised by persons with psychosocial and other disabilities, organisations of persons with disabilities, the CRPD Committee, the Special Rapporteur on the Rights of Persons with Disabilities, the UN Special Rapporteur on Health, the UN

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17 ECtHR, “Guide on Article 8 of the European Convention on Human Rights Right to respect for private and family life”. [https://www.echr.coe.int/documents/d/echr/guide\\_art\\_8\\_eng](https://www.echr.coe.int/documents/d/echr/guide_art_8_eng).

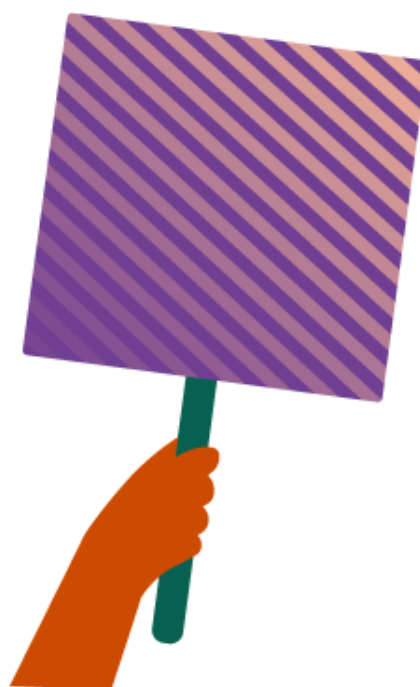
18 European Convention on Human Rights, Article 5(1)(e), [https://www.echr.coe.int/documents/d/echr/convention\\_ENG](https://www.echr.coe.int/documents/d/echr/convention_ENG).

19 Mental Health Europe, “Opposing the Draft Additional Protocol to the Oviedo Convention at the Council of Europe”, undated, <https://www.mhe-sme.org/what-we-do/human-rights/withdraw-oviedo/>.

Independent Expert on Older Persons, the Council of Europe's own Parliamentary Assembly and Human Rights Commissioner, and many civil society organizations.<sup>20</sup>

In its country reviews, the CRPD Committee has called on states to oppose the additional protocol.<sup>21</sup>

In May 2022, the Council of Europe's Committee of Ministers suspended the drafting of the additional protocol and requested the preparation of recommendations on promoting autonomy in mental health care, as well as the participation of organisations of persons with disabilities in the process.<sup>22</sup>



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20 European Disability Forum and International Disability Alliance, "EDF and IDA welcome decision of the European Court of Human Rights on the Oviedo Convention and call States to #WithdrawOviedo", 15 September 2021, <https://www.internationaldisabilityalliance.org/blog/edf-and-ida-welcome-decision-european-court-human-rights-oviedo-convention-and-call-states>.


21 See for example: CRPD Committee, "Concluding observations on the initial report of France", 4 October 2021.

22 EDF, "Joint statement welcoming the suspension of the adoption of the draft Additional Protocol to the Oviedo Convention", 7 June 2022, <https://www.edf-feph.org/joint-statement-welcoming-the-suspension-of-the-adoption-of-the-draft-additional-protocol-to-the-oviedo-convention/>.

## Forced sterilisation, abortion and contraception

Persons with disabilities, and especially women and girls with disabilities, are at risk of non-consensual medical treatment, often related to their sexual and reproductive health.

As noted above, forced sterilisation of persons with disabilities is a pervasive abuse and a gross violation of their fundamental rights. It can amount to torture and leads to life-long trauma. Nevertheless, it is ongoing and widespread across Europe. Legal capacity and forced sterilisation are intrinsically linked. Persons with intellectual and psychosocial disabilities, particularly women and girls with disabilities, and all those who can carry pregnancies and have been deprived of legal capacity, are especially at risk of being sterilised without their consent. Their legal representatives, namely guardians, courts or others, are legally allowed to take irreversible decisions about the individual's reproductive rights.

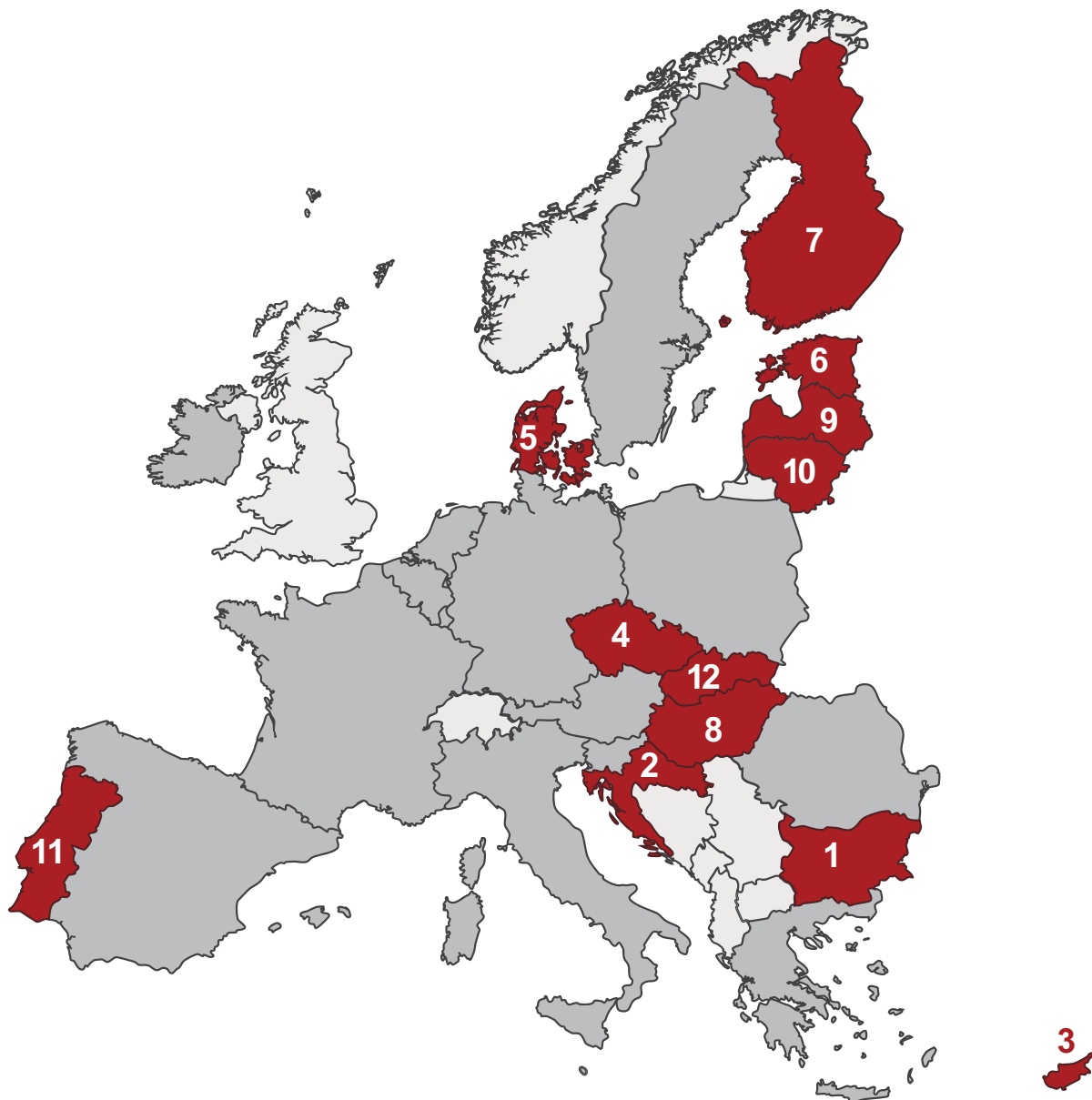


A victim of forced sterilisation, Rosario Ruiz, was threatened with separation from her partner if she did not undergo the surgery. Ruiz reflects on the surgery, saying, “What have they done with my life? Am I useless? Can everyone be a mother except me? Since then, I feel empty every day of my life.” Despite Ruiz's evident desire to be a mother, her parents had the legal power to take away her reproductive rights.<sup>23</sup>

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23 Euronews, “I see the scar and I want to die’: Why the EU allows sterilisation of women with disabilities”, 5 June 2023.

## Forced Sterilisation in the European Union



**Countries allowing some forms of forced sterilisation in their legislation:**

- |             |               |
|-------------|---------------|
| 1. Bulgaria | 7. Finland    |
| 2. Croatia  | 8. Hungary    |
| 3. Cyprus   | 9. Latvia     |
| 4. Czechia  | 10. Lithuania |
| 5. Denmark  | 11. Portugal  |
| 6. Estonia  | 12. Slovakia  |

EDF research found that at least 12 EU Member States allow some forms of forced sterilisation in their legislation: **Bulgaria, Croatia, Cyprus, Czechia, Denmark, Estonia, Finland, Hungary, Latvia, Lithuania, Portugal** and **Slovakia**. A guardian, a legal representative, an administrator or a doctor can authorise the sterilisation of a person with a disability without the individual's consent. Only 9 EU Member States explicitly criminalise forced sterilisation as a distinct offence. EDF also found that some EU Member States have recently taken initiatives to criminalise forced sterilisation or compensate victims.<sup>24</sup>

Women with disabilities in institutions are especially at risk. As just one example, in **Hungary**, the CRPD Committee interviewed women and girls with disabilities in institutions and observed that they were more likely to experience gender-based violence, including in the form of forced contraception, forced abortion, and restrictions in the exercise of their sexual and reproductive health and rights and of their parental responsibilities.<sup>25</sup>

In November 2022, the ECtHR ruled that three women with disabilities in a psychiatric institution in **Moldova** had been subject to inhuman and degrading treatment as a result of abortions they were forced to undergo with “gross disregard for their right to autonomy and choice”, after having been raped by the head doctor of the institution and becoming pregnant.<sup>26</sup> It also found that one of the women had been subject to forced contraception, in the form of an intrauterine device.<sup>27</sup> A later investigation revealed that the head doctor had raped at least 16 patients, reflecting the particular threats and risks women with disabilities confined in institutions can face.<sup>28</sup>

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24 EDF, “Forced sterilization of persons with disabilities in the European Union”, September 2022, [https://www.edf-feph.org/content/uploads/2022/09/EDF\\_FS\\_0909-accessible.pdf](https://www.edf-feph.org/content/uploads/2022/09/EDF_FS_0909-accessible.pdf).

25 CRPD Committee, “Inquiry Concerning Hungary under Article 6 of the Optional Protocol to the Convention”, 17 September 2020.

26 ECtHR, G.M. and Others v. the Republic of Moldova, application no. 44394/15, 22 November 2023.

27 ECtHR, G.M. and Others v. the Republic of Moldova, application no. 44394/15, 22 November 2023. Although the women had not been legally deprived of their legal capacity, they were de facto stripped of legal capacity by being under the control of the authorities while confined in the institution.

28 European Centre for Law and Justice, “ECtHR: Forced Abortion and Contraception are Inhumane Treatment”, 23 November 2022, <https://eclj.org/abortion/echr/cedh-lavortement-et-la-contraception-forces-sont-des-traitements-inhumains>.

The Moldovan legal framework regarding informed consent and persons with disabilities also had a significant role in the abuses.

The Court found that, contrary to obligations to ensure bodily integrity, Moldovan laws lacked a requirement to obtain valid, free and prior consent for medical interventions from persons with intellectual disabilities, adequate criminal legislation to dissuade the practice of non-consensual medical interventions carried out on persons with intellectual disabilities, particularly women, and other mechanisms to prevent such abuse on persons with intellectual disabilities, particularly women and particularly those in institutions.<sup>29</sup>

Even beyond the context of institutions, the ECtHR has found that “sterilisation bears on manifold aspects of the individual’s personal integrity”, including physical and mental well-being and emotional, spiritual and family life. The Court has determined that states have a positive obligation to ensure effective legal safeguards to protect women from non-consensual sterilisation.<sup>30</sup>

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29 ECtHR, *G.M. and Others v. the Republic of Moldova*, application no. 44394/15, 22 November 2023.

30 ECtHR, “Guide on Article 8 of the European Convention on Human Rights Right to respect for private and family life”.

## Institutionalisation

Deprivation of legal capacity leads to institutionalisation, lengthens institutionalisation, hinders deinstitutionalisation and impedes independent living.<sup>31</sup>

Across the EU, 1.4 million persons with disabilities continue to be confined to residential institutions, especially those with intellectual disabilities.<sup>32</sup> Inclusion Europe revealed that in 2023 around 750 000 people with intellectual disabilities were living in segregated “care” institutions with 30 persons or more in one place and 39 000 in psychiatric hospitals.<sup>33</sup>

Many of the people with disabilities institutionalised are deprived of legal capacity, wholly or partially. The decision about their institutionalisation has been made by a guardian, usually a relative, often against the person’s will or without their informed consent. As one example, according to a European Union Agency for Fundamental Rights research study, in **Bulgaria** and **Slovakia** almost all people living in institutions are deprived of their legal capacity. The director of an institution generally acts as guardian for all residents.<sup>34</sup> In some cases, the placement of persons with disabilities in institutions has been motivated by relatives’ own interests, for example concerning property ownership.<sup>35</sup>

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31 ENIL, “Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union”, February 2022.

32 Including children. Šiška J., Beadle-Brown J., “Report on the Transition from Institutional Care to Community-Based Services in 27 EU Member States”, Research report for the European Expert Group on Transition from Institutional to Community-based Care, 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf>.

33 Inclusion Europe, “Inclusion Indicators 2023”, <https://str.inclusion.eu/4fbaa7b98fcf6c493d7f54e03.pdf>.

34 FRA, “From Institutions to Community-based Living: Perspectives from the Ground”, 2018, [https://fra.europa.eu/sites/default/files/fra\\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\\_en.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives_en.pdf).

35 ENIL, “Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union”, February 2022.



Another example from **Italy** shows that institutionalisation is still widespread. Placement in institutions is allowed by law and implemented by tutelary judges, guardians and support administrators, without having consulted and obtained the consent of the person concerned.<sup>36</sup>

### **Institutionalisation and abuse in Poland**

“My child’s nightmare lasted around a year and a half. She was beaten and locked in a caged bed, sometimes for the entire day or even two days.”

This is how a mother described the ordeal her daughter Kasia (pseudonym) went through in a residential institution for girls and women with intellectual disabilities in Jordanów, a small town in southern Poland. Having entered two months before her 18th birthday, when Kasia was removed from the institution almost two years later, her family said she was barely able to speak or walk, a side effect of the medication she was given.<sup>37</sup>

The deprivation of legal capacity also results in the lack of direct access to the justice system, meaning people are unable to challenge their institutionalisation and leave. As noted above, those confined to institutions can be subject to inhuman and degrading conditions<sup>38</sup> and the use of solitary confinement, seclusion, chemical and mechanical restraints sometimes lead to their death.<sup>39</sup>

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36 Information provided by the Italian Disability Forum.

37 Report: Human Rights Watch, “Horror Behind Closed Doors of Polish Residential Institution – Women and Girls with Intellectual Disabilities Beaten, Tied, and Locked in Caged Bed”, June 2022, <https://www.hrw.org/news/2022/06/24/horror-behind-closed-doors-polish-residential-institution>.

38 For example, see Euractiv, “Romania horrified by inhumane abuse in care centres for disabled”, July 2023, <https://www.euractiv.com/section/politics/news/romania-horrified-by-inhumane-abuse-in-care-centres-for-disabled/>.

39 See for example: Inclusion Europe, “Deaths and abuse of people with severe intellectual disabilities and autism in Czechia - Respekt magazine investigation”, <https://www.inclusion-europe.eu/deaths-and-abuse-of-people-with-severe-intellectual-disabilities-and-autism-in-czechia-respekt-magazine-investigation/>.

### **Institutionalisation and forced sterilisation in Austria**

Institutionalisation can also make women more vulnerable to sterilisation, as in the case of a 34-year-old woman from Tyrol (Austria). In 2009, she was forced to sign the consent form for her tubal ligation without reading the terms of the surgery. Further, the institution threatened her with expulsion from their care if she did not have the surgery. Unable to challenge their authority and dependent on their care, she was sterilised. Reflecting on the surgery, she said “I no longer had trust in people, I was so disappointed and so hurt. I don’t feel like a woman anymore.”<sup>40</sup>

In some of its jurisprudence, the ECtHR has condemned the detention of persons with disabilities in psychiatric hospitals and the lack of remedies available to them to challenge incapacitation decisions, which led to their institutionalisation. This includes the 2012 judgment in the *Stanev v. Bulgaria* case.

### **Detention in psychiatric hospital in Bulgaria: the *Stanev v. Bulgaria* case**

Mr. Stanev, a man with a psychosocial disability, was deprived of his legal capacity and placed under partial guardianship of a government worker at the request of his relatives. The guardian placed him in an institution against his will where he was subjected to poor living conditions and physical violence. Mr. Stanev had no ability to challenge this situation as he could not initiate any legal proceedings, including a proceeding to have his guardianship lifted, without his guardian’s consent. The Court found that Mr. Stanev had been unlawfully deprived of his liberty, subject to degrading treatment, and denied the right to a fair trial. Significantly, it also recognised that an individual’s legal capacity is vital for the exercise of all human rights and fundamental freedoms.<sup>41</sup>

40 <https://oe1.orf.at/artikel/318640/Zwangssterilisationen-in-Oesterreich>

41 ECtHR, *Stanev v. Bulgaria*, application no. 36760/06, 12 January 2012. The decision did not address Stanev’s claims under Article 8, which left numerous issues related to the infringement of rights of persons with disabilities resulting from institutionalization unaddressed. Nelson L., “*Stanev v. Bulgaria: The Grand Chamber’s Cautionary Approach to Expanding Protection of the Rights of Persons with Psychosocial Disabilities*”; and Ferri D., Broderick A., “*The European Court of Human Rights and the Human Rights Model of Disability: Convergence, Fragmentation and Future Perspectives*”.

## Summary

- Deprivation of legal capacity is pervasive in Europe and it leads to a serious, recurrent violation of human rights.
- Women with disabilities are more likely to be deprived of legal capacity and have their rights violated because of it.
- Despite this, the legal system – including the European Court of Human Rights – does not fully apply the CRPD’s interpretation, leading to accepting violations of the rights of persons with disabilities as lawful.
- The most remarkable human rights abuses enabled by deprivation of legal capacity include forced and coerced treatment; forced sterilisation, contraception and abortion that in turn enable sexual abuse and exploitation; and institutionalisation that leads to violence, abuse and neglect.

[Back to Contents](#)

## Chapter 5:

# Promising practices



In addition to addressing the legal framework's shortcomings described in the preceding chapter, EU Member States should ensure that policies enable supported decision-making arrangements in line with the CRPD. Governments should also develop and promote tools to support the collection of free and informed consent, and foster dignity and autonomy in health care setting, including mental health care.

## Moving from substitute to supported decision-making

Chapter 2 outlines the key elements for rights-respecting supported decision-making systems. The UN Special Rapporteur on the Rights of Persons with Disabilities has identified some key elements regarding policy frameworks governments should incorporate, including:<sup>1</sup>

- a comprehensive system to coordinate access to supported decision-making, including in rural and remote areas;
- promoting the creation and sustained operation of community-based supported decision-making alternatives;
- ensuring adequate resources;
- promoting pilot projects;
- undertaking or promoting research on supported decision-making.

Governments must actively involve and consult persons with disabilities and their representative organisations in the development of relevant laws, policies, and programmes.

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1 General Assembly, Report of the UN Special Rapporteur on the Rights of Persons with Disabilities, A/HRC/37/56, 12 December 2017, para. 84(c).

A number of promising practices in supported decision-making exist and are emerging in some EU Member States, including programmes organised by governments as well as ones led by civil society organisations. This chapter describes a few examples of different types of services.<sup>2</sup>

## Sweden: Personal Ombud Programme

The Personal Ombud system in Sweden is one model of supported decision-making, in which an individual provides support to a person with psychosocial disabilities.<sup>3</sup> In 2000, the government established it as a nationwide system with approximately 300 ombudspersons who support 6 000 to 7 000 persons with psychosocial disabilities.<sup>4</sup> The support offered is voluntary, highly flexible and adaptable to the specific requirements of the person with a disability. The ombudsperson works at the request of a person with a disability and adapts to their needs and schedule, meeting them at home or other convenient locations. They assist in areas including health care, housing, access to services, employment, family issues, and assisting people who would like to challenge the partial guardianship still legal in Sweden.<sup>5</sup> The system operates under an overarching Personal Ombudsman management body consisting of representatives from local government, primary care and psychiatric health services, employment and social insurance services, local advocacy groups and/or organisations of people with lived experience.<sup>6</sup> Research has found key positive benefits,

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2 See also: EASPD, “Models on innovative practices focusing on supported decision-making mechanisms”, December 2021; and MHE, “Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs”. Additionally, throughout the WHO’s QualityRights training materials there are various examples of good practices, including especially: WHO, “Guidance on Community Mental Health Services: Promoting Person Centered and Rights-Based Approaches”, 2021, <https://www.who.int/publications/i/item/9789240025707>.

3 “Personal Representative [Ombudsman]”, <https://kunskapsguiden.se/omraden-och-teman/psykisk-ohalsa/personligt-ombud/>.

4 Zero Project, “Personal Ombudsman in Sweden”, 19 December 2021, <https://zeroproject.org/policy/sweden-2/>.

5 WHO, “Supported decision-making and advance planning. WHO QualityRights Specialized training. Course guide”, 2019, Geneva.

6 EASPD, “Models on innovative practices focusing on supported decision-making mechanisms”.

including improved well-being and independence for persons with disabilities and less cost on the social service system.<sup>7</sup> In March 2024, the CRPD Committee recommended that Sweden review the programme to consider its application to all persons with disabilities and to ensure national coordination and consistency across municipalities.<sup>8</sup>

In Catalonia, **Spain**, the organisation Support-Girona provides assistance based on a similar model.<sup>9</sup>

## Finland: Open Dialogue

The Open Dialogue model is a practice originally developed in Finland, as an alternative to the traditional mental health system for people diagnosed with psychosocial disabilities. It is an example of community-based mental health support programme. This approach respects the decision-making power of the person concerned, including about where to meet, and engages the person's network of family and friends. The approach is not medicalised, is flexible and adapts to the changing needs of the person. A strong emphasis is placed on transparency in treatment planning, and on decision-making processes respecting a person's will and preferences and safeguarded from undue influence. It also enables the members of the network to openly voice and reflect on their thoughts and feelings. Such support enables the person to retain their legal capacity and to make the final decision on, for example, their treatment, after exchanges and reflection within the group.<sup>10</sup>

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7 EASPD, "Models on innovative practices focusing on supported decision-making mechanisms"; and WHO, "Supported decision-making and advance planning. WHO QualityRights Specialized training. Course guide".

8 CRPD Committee, "Concluding observations on the combined second and third periodic reports of Sweden", para. 28.

9 <https://supportgirona.cat/>

10 WHO, "Supported decision-making and advance planning. WHO QualityRights Specialized training. Course guide"; and ENNHRI and MHE, "Implementing Supported Decision-Making: Developments across Europe and the role of NHRIs".

## Various Countries: Personal Assistance Budgets

Several European countries have Personal Assistance Budget systems, which, while not exactly a supported decision-making system, can be significant in increasing opportunities for persons with disabilities to make decisions about their lives.<sup>11</sup> A Personal Assistant Budget is a user-centred funding mechanism, in which an amount of money is given to a person with a disability by the public authorities. It is for the person to decide how to use this budget to meet their support needs and arrange the support. **Czechia, Ireland, Italy** and **Spain** are currently implementing initiatives in line with the personal budget model. **Finland** and **Sweden** have already introduced Personal Assistance Budgets in national law and have been adapting and extending the model.<sup>12</sup>

However, budgetary cuts often threaten such programmes. The region of Flanders in **Belgium** was implementing a personal assistance budget under which the holder was deciding who works as an assistant, for which assignments, at what time, and where and how the assistance would take place.<sup>13</sup> However, insufficient budget or a potential budget cut may threaten the programme and the payment of the personal budget. The organisation GRIP reported that the government does not invest enough financial means to put the right to support to personal assistance in practice and that there are no actions to make sure there are enough good personal assistants in the labour market. There are also fears that potential budget cuts will threaten the programme in **Finland**.

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11 See: UNIC - towards User-centred fuNdlng models for long term Care, “Models of Good Practice Report on Personal Budgets”, June 2021, <https://www.unicproject.eu/wp-content/uploads/2021/09/2.1-Models-of-Good-Practices-report.pdf>.

12 EASPD, “Models on innovative practices focusing on supported decision-making mechanisms”; and Zero Project, “The Right to a Personal Assistance Budget”, 19 December 2021, <https://zeroproject.org/view/project/cceaa677-5423-eb11-a813-000d3ab9b226>. Austria (the city of Salzburg) used to also offer personal budget as part of a 3-year project, which has now been terminated.

13 Zero Project, “Flanders’ Personal Assistance Budget”, 19 December 2021, <https://zeroproject.org/view/project/8ccaff4e-5423-eb11-a813-0022489b3a6d>.



## Understanding and collecting free and informed consent

As noted above, informed consent for medical and other services is an essential component of enjoying the right to legal capacity, as well as other rights, including to bodily integrity, and the right to be free from inhuman and degrading treatment.

The Special Rapporteur on the Rights of Persons with Disabilities has noted that providing support to persons experiencing an emotional crisis and severe distress can pose certain difficulties in obtaining informed consent. However, the support paradigm offers a rights-based approach.

### Training and material

The development of training and material on legal capacity and consent can support professionals, families, friends and other persons in contact with persons with disabilities, to respect the autonomy, as well as the will and preferences of the person with a disability, even in situation of crisis.

In 2019, the WHO published its QualityRights materials for training, guidance and transformation<sup>14</sup> to build capacity among mental health practitioners, persons with disabilities, families, care partners and others, on how to implement a human rights and recovery approach in the area of mental health in line with the CRPD and other international human rights standards. The training materials include a core training, covering human rights principles as well as legal capacity. They also include specialised trainings, for example on supported decision-making and advance planning, and a course for transforming services.

Many organisations of persons with disabilities and other civil society organisations developed their own tools to promote autonomy and free and informed consent.

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14 <https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools>

Ensuring that persons with disabilities know and understand their rights is an essential part of guaranteeing informed consent.

In Belgium, the association Esenca developed a toolkit on contraception and sterilisation aimed at persons with disabilities and their support persons,<sup>15</sup> including a version in Easy to Read.<sup>16</sup>

## Advance planning

Advance plans (or advance directives), allow persons with disabilities to give instructions on how to deal with future emotional crises and/or to appoint a person to support them in those circumstances.<sup>17</sup>

### **Difference between powers of representation (or “private mandate”) and advance plans**

Advance plans or advance directives are different from a power of representation or private mandate.

The terms “power of representation” or “private mandate” are used to refer to such power that may be granted by an adult, under a contract, or a unilateral act, to be exercised when the grantor is not in a position to act in their interests.

An advance directive or “living will” is an instruction given by a person, when they still have full capacity, providing guidelines in case the person becomes unable to express their preferences. Such directives may relate to health care and end-of-life decisions.

It may be that an adult grants a private mandate and also issues advance directives.

15 <https://www.esenca.be/wp-content/uploads/2022/12/Brochure-esenca-liege-de-la-contraception-a-la-sterelisation-Print-comprimee.pdf> (in French)

16 <https://associations-solidaris-liege.be/wp-content/uploads/2022/05/ASPH-De-la-contraception-a-la-sterelisation-FALC-Print.pdf> (in French)

17 General Assembly, Report of the UN Special Rapporteur on the Rights of Persons with Disabilities, A/HRC/37/56, 12 December 2017, para. 32, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/360/32/PDF/G1736032.pdf?OpenElement>.

Much of the research on advance directives in Europe appears to focus on the frequency of their use, primarily in the context of end-of-life decisions. Overall, the use of advance directives or advance care plans remains low in Europe, with some variation across countries, due to lack of knowledge or bureaucratic obstacles, among other reasons.<sup>18</sup>

A study in **Portugal** found that there were positive attitudes among the population towards advance care planning and noted the importance of community-based practices in encouraging the use of advance directives tailored to individuals and responsive to their needs. It found that “Community-based initiatives are a promising roadmap for bringing planning options to a broad audience, tailoring programmes to meet the distinctive social, cultural, and religious needs of the particular populations they serve.”<sup>19</sup>

### Psychiatric advance directives

Research in recent years in a variety of countries on psychiatric advance directives (PADs) has found a 25% reduction in compulsory admissions for psychiatric treatment for people with PADs compared to usual care, and that PADs lead to an improvement of “empowerment and self-determination, awareness, comprehension and appropriation of symptoms and partnership.”<sup>20</sup>

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- 18 For example: Dupont C., De Vleminck A., Deliens L., Gilissen J., “Advance Care Planning in Belgium”, *Z Evid Fortbild Qual Gesundhwes*, August 2023, 180:121-126, <https://www.gbhi.org/news-publications/advance-care-planning-belgium>; and Andreasen P., Finne-Soveri U.H., Deliens L. on behalf of PACE consortium, et al., “Advance directives in European long-term care facilities: a cross-sectional survey”, *BMJ Supportive & Palliative Care*, 2022, <https://spcare.bmj.com/content/12/e3/e393>; and Herreros B., Benito M., Gella P. et al., “Why have Advance Directives failed in Spain?” *BMC Med Ethics*, 2020, 21:113, <https://doi.org/10.1186/s12910-020-00557-4>.
- 19 Laranjeira C., Dixe M.D.A., Gueifão L., Caetano L., Passadouro R., Querido A., “Awareness and Attitudes towards Advance Care Directives (ACDs): An Online Survey of Portuguese Adults”, *Healthcare (Basel)*, 29 May 2021, 9(6):648, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8227883/>.
- 20 De Jong M.H., Kamperman A.M., Oorschot M. et al., “Interventions to reduce compulsory psychiatric admissions: a systematic review and meta-analysis”, *JAMA Psychiatry*, 2016, 73(7):657-664, <https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2526002>; and Molyneaux E., Turner A., Candy B., Landau S., Johnson S., Lloyd-Evans B., “Crisis-planning interventions for people with psychotic illness or bipolar disorder: systematic review and meta-analyses”, *BJPsych Open*, 2019, 5(4):e53, <https://pubmed.ncbi.nlm.nih.gov/31530302/>.

In Europe, a participatory research study in Marseilles, **France**, between January 2019 and June 2021 among people diagnosed with psychosocial disabilities and with PADs facilitated by a peer, found a 32% reduction in forced admissions among people with PADs, compared to those without. Those with PADs also exhibited lower self-perceived symptoms, greater empowerment and higher recovery, according to the study. The study also noted the importance of encouragement, explanation and facilitation among peers and individuals with disabilities in the creation of a PAD. It concluded that involving peer workers in the completion of PADs supports the current shift of mental health care from substitute decision-making to supported decision-making.<sup>21</sup>

## Autonomy and support in mental health

Respect for the right to legal capacity also involves respecting people's right to consent to or refuse treatment.<sup>22</sup> In the mental health service context, this means that mental health systems and services must shift away from a more medical model, which relies on diagnosis and medication, to include a holistic and community-based approach. A person-centred, human-rights based approach considers people in the context of their whole lives, respecting their will and preferences in treatment, implementing alternatives to coercion, and promoting people's right to participation and community inclusion. The WHO asserts that countries that apply this approach "will vastly improve not only the lives of people with mental health conditions and psychosocial disabilities, but also their families, communities and societies as a whole."<sup>23</sup>

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21 Peer-Worker-Facilitated Psychiatric Advance Directive Study (French acronym DAiP): Tinland A., Loubière S., Mougeot F. et al., "Effect of Psychiatric Advance Directives Facilitated by Peer Workers on Compulsory Admission Among People With Mental Illness: A Randomized Clinical Trial", *JAMA Psychiatry*, 2022, 79(8):752–759, doi:10.1001/jamapsychiatry.2022.1627.

22 WHO, "Legal Capacity and the Right to Decide. WHO QualityRights Core training: mental health and social services".

23 WHO, "Guidance on Community Mental Health Services: Promoting Person Centered and Rights-Based Approaches".

Known as the “recovery approach”, this paradigm aims to address the full range of social determinants that impact people’s mental health, including relationships, education, employment, living conditions, community and other aspects. Rather than isolating and controlling a person with disabilities, the recovery approach focuses on connectedness; hope and optimism about the future; rebuilding or redefining a positive identity; pursuing a meaningful life; and empowerment through personal responsibility.<sup>24</sup>

Community-based mental health services have been shown to reduce the use of forced medication, restraints and forced placement in facilities. They also promote decision-making and informed consent for treatment by persons who are most at risk of being subject to coercive practices. Community-based mental health services can take different forms, including crisis services, community outreach, peer support, hospital-based services, supported living services and community mental health centres.<sup>25</sup>

## Open Dialogue approach

The Open Dialogue approach, described above, is one example of a community-based approach to supporting people with psychosocial disabilities. The Trieste network of community mental health services in **Italy** is also founded on a human rights-based approach, to support and involve a network of community mental health centres, active 24 hours a day, 7 days a week. The network aims to support persons with disabilities, including those who experience severe distress. Each person using a community mental health centre is assigned a small multidisciplinary group of staff, that becomes responsible for their care and support. The centres are also available to people who wish to visit periodically for individual and group therapy sessions and meetings, medication support, informal contact with others, or to share a meal together. Community mental health centres also provide

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24 Gooding P., McSherry B., Roper C., Grey F., “Alternatives to Coercion in Mental Health Settings: A Literature Review”, *Melbourne Social Equity Institute*, 2018, [https://socialequity.unimelb.edu.au/\\_data/assets/pdf\\_file/0012/2898525/Alternatives-to-Coercion-Literature-Review-Melbourne-Social-Equity-Institute.pdf](https://socialequity.unimelb.edu.au/_data/assets/pdf_file/0012/2898525/Alternatives-to-Coercion-Literature-Review-Melbourne-Social-Equity-Institute.pdf).

25 WHO, “Guidance on Community Mental Health Services: Promoting Person Centered and Rights-Based Approaches”, <https://iris.who.int/bitstream/handle/10665/341648/9789240025707-eng.pdf>.

outreach activities, home visits, crisis support at home, and support for individuals to access education, employment, social or leisure-related services in the community. The service has resulted in a reduction of coercive measures and better outcomes for persons with psychosocial disabilities, including fewer relapses and improved integration into the community.<sup>26</sup>

On a smaller scale, the Kliniken Landkreis Heidenheim is a mental health clinic, located in a small rural town, Heidenheim, in south-west **Germany**. It is a flexible, user-oriented and community-based mental health service to support people with psychosocial disabilities and prevent coercion. All services are available without delay or waiting lists, including outpatient services, inpatient services, day clinics, and home treatment and support, as preferred by the user. Service users select from the therapeutic activities offered, which include group and individual psychotherapy, peer support, social assistance, and art, dance/movement and occupational therapy. In addition, it has direct links with community groups and social service providers.<sup>27</sup>

## Summary

- Despite the stark environment, there are promising practices that can be scaled up and replicated.
- These include personal ombuds, advance directives, as well as adapting training and material to guarantee free and informed content.
- There are also specific practices to guarantee mental health care, that focus on a holistic recovery model and on community living, instead of medicalising. These practices includes the Open Dialogue approach and community-based clinics.

[Back to Contents](#)

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26 WHO, "Guidance on Community Mental Health Services: Promoting Person Centered and Rights-Based Approaches"; and Gooding P. et al., "Alternatives to Coercion in Mental Health Settings: A Literature Review".

27 EASPD, "Models on innovative practices focusing on supported decision-making mechanisms".

## Chapter 6:

# Conclusions and recommendations



As this report shows, persons with disabilities continue to be deprived of their legal capacity all over Europe. As a result, they are not allowed to make decisions about their lives and face numerous human rights violations. This goes on despite the ratification of the CRPD by all European countries and the European Union itself.

Most European countries, including all EU countries and the European Union itself, failed to adopt measures to promote and protect the legal capacity of persons with disabilities. Worse still, the European Commission proposed a law – the regulation on the protection of adults in cross-border situations – which explicitly violates the right to legal capacity by recognising deprivation of legal capacity and placement in institutions and hospitals.

The Council of Europe has also been developing a draft additional protocol to the Oviedo Convention on Bioethics, which is not compliant with the CRPD. In addition, the European Court of Human Rights (ECtHR) failed several times to ensure human rights standards as ambitious as the CRPD in its jurisprudence.

This is in stark contrast with other international organisations. The CRPD Committee, UN experts and the WHO have developed more guidance and material to support countries in their obligation to protect this right, such as the Quality Rights initiative of the WHO.

Positively, some countries and regions have developed and are developing policies and projects to support the transition from substitute to supported decision-making regimes. Much more is still needed, however, to make the right to decide a reality in Europe.

**The European Disability Forum calls for strong actions by European countries, the European Union and the Council of Europe.**





## European Countries

### Legislation and policy:

- Abolish all forms of substituted decision-making and ensure that supported decision-making is enshrined in law and policy.
- Ban coercive measures, including forced treatment, placement, sterilisation, abortion and contraception.
- Adopt measures for the deinstitutionalisation of persons with disabilities and provide support for independent living and community-based services, with time-bound targets for the number of people entering and leaving institutions. Information about the measures and the targets should be made public and easily available, and the results should be monitored to assess the progress of the country's transition from institutional to community-based living.
- Review laws and policies to align them with Article 12 of the CRPD.
- Oppose the adoption and implementation international and European laws and policies that violate the autonomy and legal capacity of persons with disabilities.

### Support for autonomy and decision-making:

- Invest in measures supporting the autonomy and the independent living of persons with disabilities.
- Provide better-targeted support for autonomy, available free of cost to those who need it.
- Budgets for personal assistance should be delivered directly to the person with disabilities to facilitate their control.
- Ensure that service providers have sufficient resources, are trained on the CRPD, autonomy and support, and that they are monitored for CRPD violations.

**Trainings for professionals:**

- Develop and implement trainings for professionals that are in contact with persons with disabilities at national, regional and local levels.
- Focus trainings on autonomy, free and informed consent, will and preference, and the CRPD.
- Prioritise training for legal professionals (including judges), medical professionals, families and support persons.

**Opposition to international or European laws and policies that do not comply with the CRPD:**

- Policymakers should question proposals, call for amendments, and oppose adoption if they are not CRPD-compliant.

**Involvement of representative organisations:**

- Representative organisations of persons with disabilities, including self-advocate organisations and those for persons with intellectual and psychosocial disabilities, must be closely involved and consulted.
- Pay particular attention to older people, including those with dementia, and women with disabilities.

**European Union****Legislation and policy:**

- Ensure new legislative or policy proposals, as well as funding programmes, do not violate Articles 12 (Equality before the law), 14 (Liberty and security of the person) and 19 (Living independently and being included in the community) of the CRPD.
- Amend the European Commission's proposal for the Regulation on the Protection of Adults in Cross-border Situations proposed by the European Commission, as its original text violates the CRPD.

- Revise European Election Law to ensure voting and candidacy rights for all persons with disabilities, regardless of legal capacity.
- Criminalise forced sterilisation, in line with the Istanbul Convention on combating violence against women and domestic violence.
- Revise any current law or proposal not aligned with Articles 12, 14 and 19 of the CRPD.

### **Guidance and support to EU Member States:**

- Provide guidance on the right to legal capacity and supported decision-making.
- Provide guidance on deinstitutionalisation and support to independent living and community-based services, and link this guidance to the rules governing the use of EU Cohesion funding in the Member States.
- Facilitate the exchange of good practices to support Member States in legal capacity reforms.
- Adopt recommendations against coercion in various areas.

### **Research:**

- Collect data on deprivation of legal capacity and coercive measures.
- Conduct research on effective supported decision-making regimes and existing measures to collect free and informed consent.



## Council of Europe

### **Withdrawal of draft additional protocol to the Oviedo Convention:**

- Withdraw the proposed draft additional protocol to the Oviedo Convention dealing with involuntary treatment and placement in psychiatry and violating the CRPD.
- Focus on the adoption and implementation of strong recommendations on autonomy in mental health settings.

### **Support for legal capacity and prevention of coercion:**

- Support the exchange of good practices to ensure the legal capacity of persons with disabilities.
- Promote initiatives aiming to end coercion in all areas of life.

### **Action against coercion faced by women and girls with disabilities by the Council of Europe Group of Experts on Action against Violence against Women and Domestic Violence (GREVIO):**

- Adopt strong recommendations to end coercion faced by women and girls with disabilities.
- Pay particular attention to coercion of women and girls with disabilities and adopt targeted recommendations to end coercion, when evaluating the implementation of the Istanbul Convention by countries.

### **Respect for disability rights by the European Court of Human Rights:**

- Refrain from adopting judgments that do not respect disability rights as enshrined in the CRPD.
- Ensure consistent reference to the CRPD in judgments related to cases involving persons with disabilities.



**Stay updated with our actions:**