

The right to make financial decisions

**Briefing on the right of persons with intellectual
disabilities to decide about their money**

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Introduction

The **right to control your own money and make financial decisions** is key to be autonomous, live independently and make your dreams come true.

The ability to make choices about your finances is certainly one of the conditions to full inclusion. While this is something people normally take for granted, many persons with disabilities, especially with intellectual disabilities, cannot.

Restricting the capacity to make financial decisions clear comes from the limitations to legal capacity imposed on many people with intellectual disabilities.

Problems with substituted decision

Legal capacity is an enabler of rights or, in other words, the **right to have rights** and to **exercise them**. This means having rights and responsibilities, but also that the person can exercise, claim and defend those rights and fulfil those responsibilities.

Legal capacity acts “as a sword to enable one to make one’s own choices” and “as a shield fending off others when they purport to make decisions for us —even when well-intentioned”¹

Legal capacity is necessary for many other aspects of life:

- choose where and who you live with;
- vote and be elected;
- make healthcare decisions;
- get married and have a family;
- **have a bank account, control your own money and property, sign contracts.**

Legal capacity restrictions are frequent for people with intellectual disabilities. As a consequence, they also have many restrictions to the decisions they can do on their own.

Denial of, or restriction to, their legal capacity is usually justified:

- on the basis of a medical condition (status approach),
- because of a previous “poor” decision (outcome approach),
- because they are perceived not intelligent enough (functional approach).

¹ Legal capacity law reform: The revolution of the UN Convention on the rights of persons with disability by Gerard Quinn, Professor of Law, Director, Centre for Disability Law & Policy, NUI Galway <http://frontline-ireland.com/legal-capacity-law-reform-the-revolution-of-the-un-convention-on-the-rights-of-persons-with-disability/>

The measures are discriminatorily applied to people with disabilities and presume to be able to know what a person thinks, and assume that people without disabilities think better.

Once legal capacity is limited, persons with disabilities are normally put under a **substituted decision-making** regime, where a legal representative (or guardian) is chosen to make decisions for them.

Although each national legal framework has its own system, **substituted decision-making** regimes can be traced back to two models:

- **plenary guardianship** is the most severe. It means a third person takes over the right to make all decisions and totally cancels the person's self-determination.
- **partial guardianship** means person maintains the right to make certain kinds of decisions.

People under **plenary guardianship** are **deprived of all or almost all of their capacity to make financial decisions**. The involvement of the guardian is necessary to take decisions on financial matters.

Under **partial guardianship**, people retain limited financial self-determination, which means they can **make smaller everyday** transactions. However, it is the guardian who makes the most important financial decisions.

In both cases, contracts made by a person with limited legal capacity **can be annulled**.

These systems are not in line with international treaties recognising legal capacity as a core human right of persons with disabilities.

It must also be changed because:

- **Overprotection disproportionately impacts** individuals' possibilities to enjoy their goods and money.
- It leads to the **disempowerment**, people have no possibility to learn from their mistakes.

- Persons with disabilities may be exposed to **economic exploitation** by guardians with bad intentions.
- It strengthens the **stereotype of persons with disabilities who are unable to control and manage their money.**

International law

Equality before the law, and legal capacity

Article 12 of the **United Nation's Convention on the Rights of Persons with Disabilities (CRPD)** is the key provision when it comes to the ability of persons with disabilities to decide about their own finances.

Article 12 does not provide for additional rights for people with disabilities. It simply describes the elements that State Parties are required to consider to ensure the right to equality before the law of persons with disabilities.

In its first two paragraphs, the Article affirms that:

- *"persons with disabilities **have the right to recognition everywhere as persons before the law**"*
- States Parties *"shall recognize that persons with disabilities enjoy **legal capacity on an equal basis with others in all aspects of life**"².*

As the CRPD Committee affirmed in its General Comment no. 1, **equality before the law** compounded by **unrestricted legal capacity** is a **fundamental principle of human rights protection** and a prerequisite for the exercise of other human rights as set out in the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights.³

This guarantees that everyone is respected as a person with legal capacity, regardless of disability.

² UN Convention on the Rights of Persons with Disabilities (UNCRPD), Article 12 (1)(2).

³ Committee on the Rights of Persons with Disabilities, General comment No. 1 CRPD/C/GC/1 (2014) - Article 12: Equal recognition before the law.

Right to make financial decisions

People with disabilities have **equal right**:

- to **own** or **inherit property**
- to have **equal access** to **bank loans, mortgages** and other forms of **financial credit**
- to **control their own financial affairs**⁴

The CRPD rules out any possibility to deny persons with disabilities' legal capacity for financial matters.

States must also secure **financial self-determination** so that **people with disabilities can make their own decisions** according to their **wishes** and **aspirations**.

While affirming the right to control financial affairs, the CRPD leaves **no room for legal mechanisms that replace the will of the person with disabilities by a third person**, even if they act and manage the person's asset according to what they think is the best interest of the person.

Support to making financial decisions

Persons with disabilities need solutions that meet their support needs allowing them to leave their autonomy and independence untouched.

States must *"take appropriate measures to **provide access** by persons with disabilities **to the support they may require in exercising their legal capacity**"*⁵.

Plus, **any form of substituted decision-making regime must be replaced with supported decision-making mechanisms**.⁶

⁴ UNCRPD, Article 12 (5).

⁵ UNCRPD, Article 12(3).

⁶ Committee on the Rights of Persons with Disabilities, General comment No. 1 CRPD/C/GC/1 (2014) - Article 12: Equal recognition before the law.

Support can include both **informal** and **formal arrangements**. These should vary from one person to another due to the diversity of support needs of the persons concerned.

People with complex support needs also have the right to support in making their decisions. *“Supported decision-making must be available to all. A person’s level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making”.*⁷

Support is **not a one-size-fits-all solution** but should be guaranteed in different ways, for example:

- **Supported decision-making agreements:** choosing one or more trusted support persons who assist people in exercising their legal capacity. Supporters should not act according to what they believe to be the best interest of the person; rather they have to stick to the directives of the supported person, or interpret as accurately as possible their will and preferences.⁸
- **Peer support:** people with disabilities provide knowledge, experience, emotional, social or practical help to each other.
- **Advocacy:** advocates support a person to make decisions and talk to all the other people involved.
- **Assistance with communication.**
- **Universal design** and **accessibility:** for example for banks and financial institutions to provide information in an easy-to-read format to enable persons with disabilities
- **advanced directives:** plans decided in advance that give the person a chance to state their will and preferences about future decisions when they may not be in a position to address or communicate them.

⁷ General comment No. 1 CRPD/C/GC/1 (2014)

⁸ Safeguards in measures relating to the exercise of legal capacity, 2018 <http://www.inclusion-europe.eu/wp-content/uploads/2019/11/Safeguards-in-measures-relating-to-the-exercise-of-legal-capacity.pdf>

European law

For legal capacity laws, European countries may be divided in two groups:

- Countries that introduced forms of supported decision-making
- Countries that still base their system mainly on legal capacity restriction and substituted decision-making mechanisms, ranging from partial to plenary guardianship.

Despite the ratification by all EU Member States and the European Union of the CRPD, issues related to persons with disabilities' legal capacity still remain among the most debated question.

If some countries have acknowledged that they need to change their law to be in line with the current international rules and already started a review process of their framework, legal capacity of persons with disabilities is still too often limited.⁹ The full replacement of substituted decision-making with supported decision-making is a goal that is still to be achieved for many countries.

This leads to too many people in Europe not being allowed to make important decisions about their lives, including decisions on how to make use of their money or property.

Moreover, according to the CRPD Committee, the coexistence in the national framework of substituted decision-making and supported decision-making regimes is not sufficient to fulfil article 12 of the CRPD.¹⁰ This can be an issue considering that most countries which introduced forms of supported decision-making have either maintained parallel substituted decision-making regimes in place or left substituted decision-making as a last resort solution.

⁹ See the Report of Fundamental Rights Agency (FRA), Legal capacity of persons with intellectual disabilities and persons with mental health problems

<https://fra.europa.eu/en/publication/2013/legal-capacity-persons-intellectual-disabilities-and-persons-mental-health-problems>

¹⁰ General comment No. 1 CRPD/C/GC/1 (2014)

Spain

Spain recently adopted a new reform, **Ley 8/2021**, providing for a reform of its legal capacity system based on the promotion of autonomy of persons with disabilities through support measures in the exercise of their legal capacity.¹¹

The lawmaker's intention was to adapt the Spanish legal framework to the concept of universal legal capacity as set out in Article 12 by repealing any form of limitation.

The new law imposed the shift from a paternalistic, to one based on respect for the will and preferences of the people who, through support measures adapted to people's need, are enabled to make their own decisions.

This support includes all types of measures: friendly accompaniment, technical assistance in communication, universal accessibility standards, counselling, but also delegated decision making. Only in situations where support cannot be provided in any other way, it exceptionally may take the form of representation.

The procedure leading to the provision of support can only lead to a judicial resolution that determines the acts for which the person with a disability requires support, but in **no case to restriction on legal capacity** or the **deprivation of rights**, whether personal, **patrimonial** or political.

While the reform still needs to enter into force, it appears in line with the principles of the Convention as it sufficiently safeguards and promotes persons with disabilities' autonomy and self-determination, including financial self-determination.

¹¹ See, Ley 8/2021: claves de la reforma civil y procesal para el apoyo a las personas con discapacidad

<https://noticias.juridicas.com/actualidad/noticias/16345-ley-8-2021:-claves-de-la-reforma-civil-y-procesal-para-el-apoyo-a-las-personas-con-discapacidad/>

Ireland

With the adoption of the **Irish Assisted Decision-Making (Capacity) Act 2015** (Number 64) covering **financial** and medical **decisions**, Ireland made significant progress in promoting supported decision-making by abandoning the Lunacy Regulation Act that dated back to 1871. The new act tends to move away from a 'best interests' approach for people who need support to make decisions. It provides for a rights-based approach that puts the will and preference of the person at the centre, as opposed to the old system centred on guardianship.¹²

Section 14, for instance, states:

*“(1) In exercising his or her functions as specified in the **decision-making assistance agreement**, the decision-making assistant shall:*

a) assist the appointer to obtain the appointer’s relevant information,

b) advise the appointer by explaining relevant information and considerations relating to a relevant decision,

*c) **ascertain the will and preferences of the appointer** on a matter the subject or to be the subject of a relevant decision and assist the appointer to communicate them (...),*

*d) **assist the appointer to make and express a relevant decision**, and*

e) endeavour to ensure that the appointer’s relevant decisions are implemented.

*(2) **A decision-making assistant shall not make a decision on behalf of the appointer***

¹² See Inclusion Ireland, Assisted Decision Making <https://inclusionireland.ie/assisted-decision-making/>

(3) A relevant decision taken by the appointer with the assistance of the decision-making assistant is deemed to be taken by the appointer for all purposes.”¹³

Notwithstanding these important provisions, some aspects cast doubt on the extent to which the CRPD would be properly interpreted and respected by Ireland when it comes to the legal capacity of persons with disabilities. Some argue that the new law fails to fully respect Article 12 because it says that in some cases, support might not be sufficient to protect the interest of people with disabilities, leaving room for some form of sharing or even substitution of the decision.¹⁴

First, the law contains provisions covering the appointment of **co-decision makers**, whose consequence is to significantly diminish the self-determination of the person since it leads to shared decision-making rather than supported.

Second, the courts reserve the authority to declare that a person lacks the capacity to make decisions relating to their personal welfare or property and affairs (section 37) and to establish substitute decision-making arrangements on their behalf (section 38).

Germany

In Germany, statutory custodianship (“Vormundschaft”) allowing for formal deprivation of a person’s legal capacity was abolished in 1992. The reform kept guardianship but legal guardians were obliged to act according to the wishes and aspirations of the persons concerned, who maintained their capacity as a rule. Nonetheless, the legislation was criticised,

¹³ Assisted Decision-Making (Capacity) Act 2015
<http://www.irishstatutebook.ie/eli/2015/act/64/section/14/enacted/en/html#sec14>

¹⁴ See, About legal capacity and decision-making capacity 2020, Ethical issues linked to legal capacity and decision making (full report)
<https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2020-Ethical-issues-linked-to-legal-capacity-and-decision-making-full-report/About-legal-capacity-and-decision-making-capacity>

because in practice the supported decision-making component for persons with disabilities was neglected.¹⁵

Also, in 2016 the CRPD Committee expressed concerns about Germany's guardianship law.¹⁶

In light of this, in March 2021, the German Parliament passed a law reforming current legislation that will come into force on January 1, 2023.¹⁷

The main objectives of the law are to **strengthen the self-determination** of people with disabilities, to improve the **quality of the support** in practice and implement the principle of necessity so that **guardianship is only established as a last resort**.

According to the new law, the guardian's role is to support the person in taking care of their own affairs. The support function of the guardian is thus emphasised more clearly than before. To this end, the guardian must ascertain the wishes of the person with disabilities and support their aspirations. Substituted decisions by the guardian are to be the exception.

Austria

Austria recently introduced a new reform with the intention of being in line with Article 12 of the CRPD by extensively modernising the old guardianship system. Although guardianship was originally intended to be used only as a last resort under the previous guardianship system, in practice, substituted decision-making mechanisms widely applied with a huge increase in the number of guardians being appointed at a very early stage, without any discussion with the person concerned.

¹⁵ ENNHRI Implementing Supported Decision-Making, see <https://www.mhe-sme.org/wp-content/uploads/2020/06/Report-ENNHRI-and-MHE-Implementing-supported-decision-making.pdf>

¹⁶ UN CRPD Committee, Concluding observations on the initial report of Germany, available at <https://documents-ddsny.un.org/doc/UNDOC/GEN/G15/096/31/PDF/G1509631.pdf?OpenElement>

¹⁷ See, Care legal reform - but right! - Successful! <https://www.lebenshilfe.de/informieren/familie/brr2021>

The Second Protection of Adults Act entered into force on 1 July 2018 following the motto 'Nothing about us without us'.¹⁸ The new system is centred on **autonomy, self-determination** and the **decision-making guidance** of those concerned.

The legislative process leading to the new reform was conducted with the close involvement of stakeholders and groups of interested persons, including people affected by guardianships.

The objective of the law is to **maintain and recognise the autonomy** of every individual for as long as possible and **to provide support in the management of affairs** rather than depriving people of their legal capacity and replacing their possibility to make decisions.

In brief, the new system is based on the following principles:

- **Transparency** and a **4 types of representation solutions** (also known as the four pillars), each with different levels of powers attached. The chosen solution must be recorded in a central register.
- Representation schemes apply **only to the necessary extent**.
- **Self-determination**: legal capacity is no longer restricted and as far as that the person is able to decide for themselves on a particular matter, they can act validly on their own behalf.
- A person's ability to handle their own affairs will now **no longer be assessed on medical criterias** but following a 'psychosocial model'.
- **Limited power of the courts**: the court is involved only for sensitive decisions to be made, such as permanent change of residence, disagreements between the person concerned and their representative about medical treatment, or asset management issues.

The Austrian reform represented a significant move towards the support model of the CRPD, but, **the new law did not remove forms of guardianship** from the Austrian system.

Although it is now called 'Court-appointed representation', partial guardianship constitutes the last representation model and the fourth pillar of the reform. The Court-appointed

¹⁸ The Federal Ministry of Constitutional Affairs, Reforms, Deregulation and Justice, The new adult protection law https://www.justiz.gv.at/file/2c94848a60c1583801614709bca3434b.de.0/justiz_kurzbrochuere_erwshg_en_v2.pdf?forcedownload=true

representation is intended as a **last resort** solution replacing the old guardianship system. The powers that a representative may exercise must be **restricted to a particular matter** and there is a **time limit**. It ends after the matter has been addressed or after **three years**.

*With the new law, people with intellectual disabilities
are able to decide.¹⁹*

¹⁹ <https://www.inclusion-europe.eu/with-the-new-law-people-with-intellectual-disabilities-are-able-to-decide/>

Extra-legal initiatives

Germany

The 2017 Federal Law on Participation (Bundesteilhabegesetz) promotes the establishment of independent participation counselling centres across the country, with already around 500 centres. The **Complementary Independent Participation Counselling (EUTB)** centres are counselling centres for persons with disabilities and their relatives. They offer free consultations and are adjusted to the needs of the person concerned.²⁰

Finland

Although designed for decision making on healthcare matters, the so-called **Open Dialogue model** is a practice that may successfully apply in the financial matter as well. The model aims at supporting the person to make decision with a wider networks of their choice. Service providers facilitate '**network meetings**' on a regular basis between the person and their network of friends, carers or family, and members of the healthcare team. A strong emphasis is placed on healthcare treatment planning, respect for a person's will and preferences, safeguards from undue influence. Open dialogue enables the person to maintain their legal capacity and make the final decision after dialogue within the support group²¹.

²⁰ More info on <https://www.bundesregierung.de/breg-en/service/information-material-issued-by-the-federal-government/complementary-independent-participation-counselling-eutb-englisch--1837868>

²¹ ENNHRI, Implementing supported decision-making- Developments across Europe and the role of National Human Rights Institutions 8 June 2020 <https://www.mhe-sme.org/wp-content/uploads/2020/06/Report-ENNHRI-and-MHE-Implementing-supported-decision-making.pdf>

Sweden

The Swedish Personal Ombudsman Programme is a nationwide programme that provides support in decision-making through the appointment of “**personal ombudsmen**” (PO). These professionals are highly skilled persons who perform outreach work and establish trust relationships with persons in need of support. POs assist persons in taking control of their own situation, identify care needs and ensure that people are given the necessary support. The POs should provide support to their clients in all kinds of matters, from family matters to housing, accessing services or employment. They do not make any decisions on behalf of the person concerned. The support can be stopped at any time at the request of the assisted person. The CPRD Committee said it was a good supported decision-making programme, specifically useful for persons with psychosocial disabilities²².

Scotland

The Mental Health Network is a **peer support organisation** that supports people to make advance statements. These include personal statements identifying the person’s wishes and preferences for a variety of matters ranging from medical treatment to pets and bills.²³

²² Ibid. Also see <https://zeroproject.org/policy/sweden-2/>

²³ <https://www.mhe-sme.org/wp-content/uploads/2020/06/Report-ENNHRI-and-MHE-Implementing-supported-decision-making.pdf>

Tools and resources

Safeguards in measures relating to the exercise of legal capacity, 2018 <http://www.inclusion-europe.eu/wp-content/uploads/2019/11/Safeguards-in-measures-relating-to-the-exercise-of-legal-capacity.pdf>

Legal capacity and...

- employment
- education
- citizenship
- empowerment

<https://www.inclusion-europe.eu/legal-capacity-impact-on-life-reports-employment-education/>

Plena Inclusion, Guide on how to manage money in easy-to-read, 2021

<https://www.plenainclusion.org/publicaciones/buscador/finanzas-para-mortales-guia-en-lectura-facil/>

Nous Aussi, Guide on Banks [https://data.over-blog-](https://data.over-blog-kiwi.com/0/77/01/57/20140227/ob_515076_cpnousaussimodedemploibanque.pdf)

[kiwi.com/0/77/01/57/20140227/ob_515076_cpnousaussimodedemploibanque.pdf](https://data.over-blog-kiwi.com/0/77/01/57/20140227/ob_515076_cpnousaussimodedemploibanque.pdf)



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20 million people with intellectual disabilities and their families from 39 countries.



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