



POSITION PAPER

Legal Capacity and Supported Decision- Making

Acknowledgements

This is a report of the European Association of Service providers for Persons with Disabilities (EASPD).

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Introduction

In March 2021 the European Commission launched the [European Strategy for the Rights of Persons with Disabilities](#), outlining different initiatives to undertake over the years to come. The Strategy recognises that “(...) *Legal barriers exist in particular for persons with intellectual disabilities, psychosocial disabilities or with mental health problems as they are often restricted in or deprived of their legal capacity.*” In the years to come, the European Commission aims to collect good practices on supported decision-making.

The European Association of Service providers for Persons with Disabilities (EASPD) is a European non-profit organisation representing the views of over 20,000 support services and their umbrella associations. It promotes equal opportunities for persons with disabilities through effective and high-quality service systems. Together with its members, EASPD works to make sure that care and support services are able to ensure the inclusion and the active and meaningful participation in society of all people with disabilities, while preserving their dignity, autonomy and independence.

Legal capacity - the right to make decisions and being recognised equally before the law - is a critical aspect in this regard, as it affects the recognition of a person’s ability to make decisions and exercise choice and control over their life. This is why EASPD and its members have been committed for years to promoting the recognition of the right to legal capacity for all people with disabilities, in line with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and to foster the implementation of supported decision-making, moving away from guardianship regimes and substitute decision-making approaches.

Based on the knowhow, experience and expertise of our membership, EASPD developed this paper with 3 main objectives:

1. raising awareness on the right of persons with disabilities to legal capacity;
2. urging States and the European Union to prioritise actions to support people to enjoy their right to legal capacity;
3. providing guidance to service providers on how to empower and enable the people they support in enjoying this right.

Rationale

Legal capacity is the right to make choices and be recognised before the law. This is an inherent right, granted to all people, including people with disabilities. Despite this, throughout history, individuals with disabilities have frequently been denied the same rights and responsibilities as others. Many have been prevented from exercising their rights due to assumptions about their perceived inability to comprehend or carry out certain actions, rooted in a limited societal understanding of human diversity. Consequently, legal systems worldwide have often imposed limitations on the legal capacity of individuals with disabilities, typically placing them under substitute decision-making arrangements like guardianship or curatorship. While purportedly aimed at safeguarding both individuals with disabilities and society, this practice has instead left them vulnerable, stripping away their autonomy, and diminishing their ability to engage meaningfully and contribute to society. The introduction of the UN Convention on the Rights of Persons with Disabilities

(UNCRPD) has openly challenged these assumptions, calling for a shift from such medical, paternalistic and ableist approaches towards a human rights-based approach. More recently, a new philosophy of support has begun to emerge¹,

with an emphasis being placed on how to develop support systems that go beyond keeping people solely safe and healthy and focus instead on preserving the inherent dignity, self-determination and autonomy of people, empowering and enabling them to exercise choice and control over their lives. This means that **personhood (autonomy), voice, choice and control, and social inclusion should be the objectives of support, clearly conveyed in law, policy and practice**².

The UNCRPD, in its article 12, specifically states that “persons with disabilities have the right to recognition everywhere as persons before the law” and that “States parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”³ Recognising the legal capacity of persons with disabilities is fundamental as it means respecting their autonomy and self-determination, allowing them to express their will and preferences like any other person. Because of its importance, article 12 is often referred to as the “key” article of the UNCRPD, which can trigger the full enjoyment of all other rights. As a matter of fact, when someone is denied the right to make legally binding decisions about their life, their access to other rights (such as the right to education, employment, healthcare, and political participation) may also be compromised.

Legal capacity also represents an essential precondition for the promotion of an effective transition from institutional to community-based care. It enables people with disabilities to access services and support tailored to their specific needs, wishes and preferences, making sure that they are involved in every step of the planning process, that they can make decisions about their new living arrangements, identify the type of support they need, and choose the life they want to live outside the institution.

Despite all this, persons with disabilities – in particular persons with intellectual and psychosocial disabilities and mental health problems – continue to be often deprived of their legal capacity. In the majority of European countries, substitute decision-making regimes are still widespread, thus preventing people with disabilities from making decisions for themselves in their everyday lives, seriously compromising their full inclusion and meaningful participation in society. In Europe, this issue is also acute for older persons, who have long been considered incapable of making their own decisions because of the cognitive frailty associated to ageism. This reflects an old paradigm whereby the onset of

¹ Quinn G., Gur A., Watson J., *Ageism, moral agency and autonomy: getting beyond guardianship in the 21st century*, in Israel Doron, Nena Georgantzi *Ageing, Ageism and the Law. European Perspectives on the Rights of Older Persons*, Chapter 3, Edward Elgar Publishing, Cheltenham, 30 November 2018.

² *Ibidem*.

³ UN Convention on the Rights of Persons with Disabilities, article 12.

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cognitive impairments meant an almost automatic loss of the right to make decisions for oneself and therefore the use of 'protective' mechanisms like guardianship was deemed necessary⁴.

Although some progress has been made, so far reforms have been slow in Member States and the EU has not prioritised actions and initiatives to support people with disabilities and older people to fully enjoy their right to legal capacity. It is therefore of utmost importance for the EU to move in this direction and use its influence, tools, and power to promote an effective shift towards supported decision-making systems.

Legal capacity & supported decision-making

As mentioned, legal capacity is an inherent right, granted to all people⁵. It consists of both the capacity to hold rights (legal standing) and the capacity to exercise them (legal agency). However, most of the legal frameworks tend to differentiate these two recognising the legal standing of people with disabilities (their capacity of holding rights) but not their legal agency (their capacity to exercise these rights). For example, in some cases, persons with disabilities may be legally allowed to own property but not to manage this property, such as selling it.

The UNCRPD, and its article 12 clearly affirm that persons with disabilities have the right to recognition as persons before the law and States parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. This clearly calls for a **paradigm shift from “substitute decision-making regimes”, like guardianship, towards arrangements that guarantee that persons with disabilities can make their own decisions and enjoy their rights (“supported decision-making”)**.

Article 12 of the UNCRPD also recognises that sometimes people with disabilities may require to be supported in exercising their legal capacity. It is therefore an obligation for States parties to provide persons with disabilities with access to the support necessary to enable them to make decisions that have legal effect. Such support must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making. Lastly, article 12 requires appropriate and effective safeguards to be put in place for the exercise of legal capacity. These should ensure that measures for facilitating supported decision-making are not abused, in accordance with international human rights law⁵.

⁴ Quinn G., Gur A., Watson J., *Ageism, moral agency and autonomy: getting beyond guardianship in the 21st century*, in Israel Doron, Nena Georgantzi *Ageing, Ageism and the Law. European Perspectives on the Rights of Older Persons*, Chapter 3, Edward Elgar Publishing, Cheltenham, 30 November 2018.

⁵ Committee on the Rights of Persons with Disabilities, General Comment No. 1 - Article 12: Equal recognition before the law, CRPD/C/GC/1, 11 April 2014.

From substituted to supported decision-making

Having said that, what is supported decision-making and how it differentiates from substitute decision-making?

In substitute decision-making, a person with disabilities might be considered unable to make decisions for him/herself so that a substitute decision-maker is appointed to act on the person's behalf, taking decisions on the "best interest" of the person.

In substitute decision-making people don't choose their guardian and a person can be thus appointed against their will, through a formal or informal process, where:

- A person is appointed by law to be the "guardian" of an individual. As a result, legal guardians can make some or all decisions for the person concerned, which can and often happens without prior consultation of the individual himself. This means that a person's ability to make legally effective decisions and have control over his or her life is taken away, with his or her legal capacity being removed.
- Substitute decision-making can also happen informally, with family members or friends systematically taking over all decisions for a person, including very straightforward choices about daily activities, food and clothing, as well as decisions about where, how and with whom to live, about sexual and intimate relationships, education, employment, healthcare, money management and legal choices. This occurs in clear contrast with the UNCRPD.

On the other hand, in supported decision-making people retain their legal capacity and, instead of guardians, they have supporters that enable them to make their own decisions.

More specifically, in supported decision-making:

- Person with disabilities can choose one or more trusted people to support them in making personal, financial and legal decisions.
- Instead of deciding on the basis of the "best interest" of the person, primacy is given to the person's "will and preferences", respecting their autonomy and right to decide, regardless of their disability. This approach respects the dignity and equality of individuals with disabilities and acknowledges that, like anyone else, they have unique preferences, desires, and values that should be taken into account. Moreover, this approach moves away from a paternalistic one that historically treated people with disabilities as passive subjects, with decisions taken for them without their involvement.
- The best interpretation of a person's will and preferences must always be guaranteed, even in challenging situations, such as those involving individuals with high and complex support needs. The key to achieving this goal - and therefore to avoid substitute decision-making - lies in the imperative development and recognition of additional tools and methodologies tailored to assist supporters in these circumstances⁶. It is crucial to establish, as a prerequisite for support providers, that they consistently use these methodologies before independently

⁶ An example of approach that can be particularly useful to avoid substitute decision-making and help supporters in interpreting the will and preferences of people with high and complex support needs is represented by Positive Behavioural Support (PBS). PBS is a person-centred framework for providing long-term support to people with a learning disability, including those with additional support needs such as autism, or who may be at risk of developing behaviours that challenge. Behaviour that challenges usually happens for a reason and may be the person's only way of communicating an unmet need. PBS helps supporters understand the reason for the behaviour so that they can better meet people's needs, enhance their quality of life and avoid restrictive interventions.

interpreting the individual's will. If these tools are not actively used for a specific case, it cannot be considered that every possible effort has been made to understand an individual's wishes and preferences.

SUBSTITUTE DECISION-MAKING	SUPPORTED DECISION-MAKING
In contrast with the UNCRPD	In compliance with the UNCRPD
Some people have the right to make all decisions for themselves and others do not	Everyone has the right to make decisions at all times, including decisions about whether to use support/what type of support to use in making decisions
People with intellectual and psychosocial disabilities and mental health problems do not have the capacity/ability to make their own decisions	People with intellectual and psychosocial disabilities and mental health problems are considered able to make decisions for themselves, with accommodations and/or the assistance of their supporters if desired
Assessing deficits in mental capacity (ability to make decisions)	Exploring the type and level of support that may be required to make decisions
Best interest (where others determine what is the best decision or course of action for a person)	Will and preferences (where all decisions are made by the person based on their own will and preferences and the best interpretation of their will and preferences is applied where, despite significant efforts, it is not possible to determine their will and preferences)

Table 1: Differences between substitute decision-making and supported decision-making

Guidelines for national policymakers to ensure the right of legal capacity and equal recognition before the law

As the principle of full legal capacity is established by article 12 of the UNCRPD, all States parties are required to develop a comprehensive system of supported decision-making and safeguards for all people with disabilities.

The development and adoption of legal reforms abolishing substitute decision-making and establishing supported decision-making is the first crucial step needed to guarantee the recognition and respect of the right to legal capacity for people with disabilities.

A supported decision-making regime comprises various support options that give primacy to a person's will and preferences and respect human rights norms. Here a list of the key provisions to ensure compliance with article 12 of the Convention:

- Supported decision-making must be available to all, despite the needed intensity of support;
- The provision of support to exercise legal capacity assessments should not be medical-oriented and based on mental capacity, decision-making skills, or on the persons' impairment;
- Support must be based on the will and preference of the person, and not on their perceived best interests;

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- All processes relating to legal capacity and support in exercising legal capacity should include safeguards to ensure that the person's will and preferences are respected;
- Safeguards must be established for third parties to avoid cases where the support person is not acting in accordance with the will and preferences of the person concerned⁴;
- The support person should be legally recognised, chosen by the person in need of support who should have the possibility to terminate support or change supporting person at any time;
- A person's mode of communication or their financial resources must not be a barrier to obtaining support in decision-making;
- Receiving support in decision-making should not be used as justification for limiting other fundamental rights;
- States must facilitate the creation of support when people are isolated and don't have access to naturally occurring support in the community.

It is important to highlight that supported decision-making should provide protection for all rights, such as the rights related to autonomy, to choose where to live and with whom, to freedom from abuse and ill-treatment, among others, while avoiding to overregulate the lives of persons with disabilities.

In order to be effective and consistent with the UNCRPD, **any legal reform should also take into consideration the following elements:**

1. The replacement of mental capacity assessments with the provision of support to exercise legal capacity.

People with intellectual or psychosocial disabilities and mental health problems are the most exposed to the risk of denial of their legal capacity. This often stems from mental capacity assessments that label individual as lacking decision-making skills only based on their diagnosis, resulting in denial of their legal capacity and equal recognition before the law.

The person should retain their legal capacity even when significant efforts have been made and it is still not possible to determine their will and preferences. In situations as such, the supporter must follow **the approach of the best interpretation of will and preferences** and not what they think that it is in the best interests of the person.

The intensity of the support needed to making decisions must not justify the denial of legal capacity. Preventing denial of legal capacity requires appropriate safeguards to ensure that persons with disabilities are receiving the support they need to exercise their right, including the development of holistic assessments methodologies going beyond impairments, and including individual strengths, resources, needs and challenges, with the active and meaningful participation of persons with support needs in these processes.

2. The provision of support in the exercise of legal capacity, including measures related to universal design and accessibility.

Article 12 of the UNCRPD encourages State Parties in undertaking measures “to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”⁷

⁷ UN Convention on the Rights of Persons with Disabilities, article 12.

In its General Comment 1 on article 12, the UN Committee on the Rights of Persons with Disabilities describes support as **encompassing both informal and formal support arrangements, of varying types and intensity**. Support must always give priority to a person's will and preferences, respect human rights, and with intensity tailored to individual needs.

Support can include:

- an individual choosing one or more trusted person;
- assistance with communication;
- the development and recognition of non-conventional methods of communication, especially for those who use non-verbal forms of communication;
- support with advance planning stating the will and preferences of an individual, which can be used at times when they may not be in a position to communicate their wishes to others;
- peer support.

Support should also include measures relating to:

- **Universal Design**, ensuring that products, environments, and services are usable by all people, to the greatest extent possible, without the need for adaptation or specialised design.
- **Reasonable accommodation**, with modifications and adjustments that allow persons with disabilities to enjoy and exercise on an equal basis with others all human rights and fundamental freedoms.
- **Assistive technology**, including products or technology-based services to enable individuals with disabilities to participate equally in any aspect of life.
- **Accessible information**, which is key to ensuring that people with disabilities are empowered and provided with comprehensive information which enables them to make decisions about their lives. Information provided in an understandable format or professional sign language interpretation are some examples. This is particularly important in the context of supported decision making as it allows people to receive information about support measures in a correct and accessible way and thus enables them to fully exercise free choice (including the person's right to refuse support).

3. The adoption of a co-production approach.

The design, development and implementation of any reform should be guided by a **co-production approach** in line with the **“nothing about us without us”** principle.

People can experience disability in different ways, based on their age, gender and other factors. Policy makers need to acknowledge and respect the diversity within the disability community and recognise the value it adds to the community. Therefore, persons with disabilities, their families and their representative organisations should drive and influence the reform process; at the same time, service providers and their representative organisations should be a recognised voice, with the support of a broad diversity of relevant stakeholders, each with their roles and responsibilities. States must adopt a community-based approach to the provision of decisionmaking support, building on existing social networks and community resources, and enabling the community (family, friends, neighbours, peers and others) to play a significant role in supporting persons with disabilities.

4. The inclusion of appropriate and effective safeguards and reporting mechanism to prevent abuse in accordance with international human rights law.

Safeguards for the exercise of legal capacity must include **protection against undue influence**, which occurs when “the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation”⁸. Although all people risk being subject to undue influence, this may be exacerbated for those who rely on the support of others to make decisions. The primary function or goal of safeguards is therefore to protect people with disabilities from this risk and ensure that the person’s rights, will and preferences - including the right to take risks and make mistakes - are respected. In this regard, it is extremely important to bear in mind that safeguards can never be used as an excuse to limit a person’s legal capacity or to impose another person’s will on them.

Mechanisms and safeguards must also be in place to protect the supporter. Safeguards are particularly important for service providers and their staff, by limiting the liability for a person acting following good practice when supporting a person who requires decision-making support, both formally and informally. As a matter of fact, despite the requirement for more personalised support services, the current system tends to put at legal risk those support workers who implement supported decision-making practices as they (or their employer does/can) remain legally responsible for the decisions taken by the person requiring support. On the contrary, it is essential to maintain a balance between the responsibilities of the supported individual and the support provider, respecting the individual right to take risks while also upholding the Duty of Care. The establishment of an **internal reporting mechanism for risk-related dilemmas within supported decision-making services** can be key in this respect. This mechanism should aim to prevent supporters from bearing sole responsibility and to ensure that all relevant considerations are taken into account when determining the most appropriate intervention.

5. The development and promotion of trainings and awareness-raising activities to ensure a shift in mindset and in practice.

One of the hardest tasks in the implementation of the UN Convention is about **bringing change in consolidated mindsets and perceptions to disability**. Long-lasting prejudices and assumptions about people with disabilities being unable to take decisions for themselves and live independently have undoubtedly had a serious impact on the persons themselves, their families, carers and the whole society. Civil society, civil servants and State authorities can play a key role in promoting the paradigm shift required by the Convention and support society in further developing its understanding and correct implementation.

An effective way to achieve this objective is to develop and provide information, trainings, and awareness-raising campaigns about the rights of people with disabilities and supported decision-making aimed at all stakeholders involved: persons with disabilities - who need to be aware of their right to exercise legal capacity and be able to take one’s own decisions - their families, staff working in support services and mainstream services, as well as the community at large, so that all are able to recognise the ability of people with disabilities to take their own decisions.

⁸ Committee on the Rights of Persons with Disabilities, General Comment No. 1 - Article 12: Equal recognition before the law, CRPD/C/GC/1, 11 April 2014.

6. The promotion of Self-Directed Support to further reinforce in achieving the right of persons with disabilities to make decisions and have control over their life.

Self-directed support (SDS) is an approach which puts **the person at the centre of planning and provides for support to be arranged according to the individual's real needs and aspirations**. SDS is about means shifting control to the person so they can shape the support they need to fit their needs and wishes. It has been proven that self-directed support can improve the lives of people as they have freedom to choose the support they need to achieve their aspirations in life, thus accentuating autonomy and personhood.

In 2013, Scotland introduced the [Social Care \(Self-Directed Support\) Act](#) which provided people with care and support needs four options for receiving support. Individuals can: purchase their own support and use a direct payment to pay a person or third party; direct their own support and the local council will arrange it; allow the local council to direct and arrange their support; use a combination of the previous options.

Over the years, self-directed support's components began to be developed around Europe, with personal assistance services in Sweden, personal budgets in Flanders and direct payments in the UK being a few examples. Further promoting the adoption of the SDS model can be key in making sure that people are able to make their own decisions and choices and that wishes and preferences are genuinely at the centre of all decisions that concern them.

Table 2: Reforms on legal capacity in Spain

A recent promising example of legal reform is the [Spanish Law 8/2021](#) which reformed the Spanish system into promoting respect for the will and preferences of persons with disabilities and advancing their autonomy. This Law, reforms civil and procedural legislation to promote support for persons with disabilities in the exercise of their legal capacity, moving away from the guardianship model.

Spain's main reform elements include:

- abolishing guardianship and redefining curatorship.
- it still allows representation of a person, albeit, in duly justified and exceptional circumstances. When «even having made a considerable effort, it has been impossible to determine the will, wishes and preferences of the person» and in every circumstance the person with representative powers must always take into account the life history of the person with support needs.
- it emphasises that support in the exercise of legal capacity must respect the rights, will and preferences of people with disabilities and the support person must never decide for them. Any reference to the concept of superior interest or best interest is eliminated in the legal framework and, instead, the guiding principle of the reform is based on the respect of the will, wishes and preferences of the person.
- it further establishes that while determining the support measures of individuals, under no circumstances people will be prohibited of their rights. Additionally, any type of support measure needs to be reviewed periodically and adapted if the circumstances of the person vary.
- it clarifies that it is the person who must make decisions freely and autonomously, including choosing their own support, and the information needs to be provided to them in an understandable and accessible way. However, there is not a specific measure included to guarantee this.
- it includes safeguards as a fundamental element in providing support to persons with disabilities.
- the right to receive support is conceived as a subjective right of persons with disabilities so, in principle, requesting and receiving support should not entail additional costs for persons with disabilities.

It is important to mention that in Catalonia, since 2010, year in which a substantial reform of the [Catalan Civil Code \(CCC\)](#) took place, there is an important instrument that help respect the legal capacity of people with disabilities: the assistance mechanism. According to this mechanism, a person can request the designation of one or more assistants (these can be a physical person, such as family member, relative or friend, or a legal person, such as an organisation complying with the requisites established by the Catalan Government) to assist him or her in one or different aspects of his/her life. The most important characteristic of assistance is that it is not linked to the previous absence or limitation of a person's legal capacity. Moreover, it can be terminated whenever the person enjoying support decides for it.

In Ireland, in 2015, an important legal reform took place with the signing into law of the [Assisted Decision-Making \(Capacity\) Act 2015](#). The law sets out a new framework for supported decision-making and replaces the previous system of wardship, which was considered outdated and paternalistic. Among some of its key features, the Act establishes a presumption that every person has the capacity to make decisions unless proven otherwise. This means that individuals are assumed to have capacity unless there is evidence to the contrary. Although this is not entirely in line with the UNCRPD, the new law introduces supported decision-making, allowing people with disabilities to receive assistance and support in making decisions, without having their legal capacity removed. This support can come from a relative or a friend of the person with support needs who has a relationship of trust built up over a period of personal contact. The Act also places a legal requirement on service providers to comprehensively enable a person to make a decision through the provision of a range of supports and information appropriate to their condition. Furthermore, it establishes a Decision Support Service with clearly defined functions which include the promotion of public awareness relating to the exercise of capacity by persons who may require assistance in exercising their capacity.

Table 3: The Assisted Decision-Making Act in Ireland

Recommendations to EU policymakers

The EU has several instruments in its disposal to support Member States in their efforts to realise the right of persons with disabilities to legal capacity and equality before the law, despite the fact that this is a competence lying with Member States.

In this regard, EASPD developed the following recommendations:

- ❖ **Increasing efforts using existing initiatives of the European Commission**, included in the Disability Rights Strategy 2021-2030, to:
 - **underline the importance and urgency to Member States for legal reforms restoring the legal capacity of persons with disabilities and establishing supported decision-making schemes and other alternative support options that do not limit their capacity to act** (e.g. trust asset management). The Guidance towards Member States recommending improvements to enable persons with care and support needs live independently in the community and the European Social Services of Excellence Framework are flagship initiatives that can further support towards this goal.
 - Conduct an **EU-wide study on policies and practices** to identify good examples on supported decision-making but also the state of play in different countries on reforms and practices relevant to legal capacity and supported decision-making of person with disabilities.
 - **Support the collection of tested tools to be used by professionals** to empower people with disabilities in expressing choice, voice and control over their lives and all the decisions affecting their lives.
 - Organise **mutual learning sessions** with members of the Disability Platform on legal capacity reforms.
 - Develop a **guidance / recommendations on legal capacity and supported decision-making**, along with the development of guidance to Member States on access to justice.
- ❖ **Make sure that States parties closely consult with and actively involve persons with disabilities**, in line with Art 4.3 of the UNCRPD, while implementing legal and policy reforms in this area.
- ❖ **Broadening the Knowledge Hubs** -as mentioned on the EU Care Strategy- under the Horizon Europe partnership “Transforming health and care” to facilitate transferability of knowledge and good practices and act as an exchange forum for Member State representatives and other relevant actors for relevant with legal capacity and SDM elements.
- ❖ Enabling current and new instruments to support Member States in their reforms on legal capacity and supported decision-making. The **Technical Support Instrument** is one example that can be used for this purpose.
- ❖ **Accelerating the upskilling and reskilling of the existing workforce in social services**. The Erasmus+ and the European Social Fund Plus (ESF+) programmes can be used to support this objective.
- ❖ Supporting the development of trainings and awareness-raising campaigns on supported decision-making via the **Citizens, Equality, Rights and Values programme**. Trainings can be provided through VET programmes, long-life education programmes and higher level education institutions that can increase the practical knowledge of current and future social sector professionals.

Supported decision-making in practice: guidelines on service provision

The UNCRPD calls for reshaping existing services and developing new ones to meet the evolving needs of persons with disabilities and other support needs. This indicates that the role of social services is to move towards human rights-centred and person-centred forms of support, and to empower people to live independent and meaningful lives within communities. Realising the right of persons with disabilities to live independent and meaningful lives within the communities indicates that **people shall be able to control their lives and make choices** including where to live, with whom, what type of support they want and need to receive, who they want to support them and how. As enshrined in Article 19 and General Comment 5 *“Independent living means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives”*. The establishment of supported-decision making systems is key in this regard, as they enable people to exercise their autonomy - voice, choice and control – and decide the life they want to live. Advances in supported decision-making are therefore crucial to support the transformation of services themselves, making sure they become more responsive and personalised and able to ensure the full inclusion and participation of people with disabilities in the society in which they live.

As already mentioned, persons with disabilities – and mostly persons with intellectual and psychosocial disabilities and mental health problems, as well as older people – are still often deprived from their right to make decisions. This situation not only infringes their right to legal capacity, but it also puts pressure and uncertainty on social services and their staff since the legal guardians may not always support the decisions of the individuals under guardianship. Furthermore, making decisions also involves taking risks, and support staff often struggles to find the right balance between ensuring the safety of the person they support and empowering them in enjoying their rights, including their right of making decisions which involve risks. This is even more the case if they are legally responsible for these decisions. Being properly supported and trained on the right of persons with disabilities to legal capacity and on how this shall be effectively implemented via supported decision-making process is therefore crucial. Only in this way, the care and support workforce can establish a **supported decision-making methodology** in service delivery and make sure supported decision-making become a reality for all people with disabilities⁹.

This section is about giving guidance to services providers on what are the adequate tools to shift towards empowering and supporting persons with disabilities, for them to exercise their legal capacity, make informed choices and decisions, and have full control over their lives.

⁹ [I-DECIDE](#) is an innovative promising methodology that EASPD through an EU-funded project and in collaboration with the project’s consortium has developed to encourage and offer an approach to professionals on how to support persons with disabilities to exercise their legal capacity. This methodology can be used regardless of the applicable legal frameworks in every country and can be applied at different levels or spheres of a person’s life, from high-level decisions such as getting married, having a child or living independently, to lower-level decisions.

Key elements for an effective supported decision-making methodology in service provision

To establish a supported decision-making methodology in service delivery, the following elements should be considered:

1. Following a person-centred planning approach.

Person-centred planning is an approach which helps professionals in identifying the support needs of the individual by putting the person at the centre of planning. In this type of approach, the person is supported to express how they would like their care and support to be delivered, and what goals and aspirations they want to achieve in their life through the support they receive. Person-centred planning can significantly support people with disabilities in exercising their legal capacity as individuals are supported in making decisions in the way they want, respecting their autonomy and choices and realising their wishes and preferences.

→ **Service providers should understand the importance of person-centred planning and of knowing the opinion of the person supported.** There are several person-centred tools that can be used to identify the needs, wishes and preferences of the person who draws on support, with some examples being [MAPS](#), [PATH](#), [Sorting important to/for](#), [Relationship Circle](#) and [Decision Making Agreement](#).

2. Preserving the “dignity of risk” of each individual

Human freedom involves the opportunity to exercise “dignity of risk”. This means that taking reasonable risks is a necessary part of the autonomy and self-determination of each individual. When taking a decision, people with disabilities should be free to make choices for themselves based on their will and preferences and not be forced to choose always the least risky option.

→ **Although it may be difficult to balance the Duty of Care with the individual's right to take risks, it is fundamental that supporters recognise and respect this right and that they are provided with the adequate tools and safeguards to do this.** The role of the supporters should be to help people with disabilities develop their risk-management abilities so that they can identify which decision may involve risk, what might be the risk and the consequences of making that decision.

3. Recognising and accepting the communication means of the person supported

The supported decision-making process is a relationship based on trust and, therefore, professionals should follow the means of communication that the person they support prefers and understands. Being an active listener, observing the non-verbal cues of the person supported, providing the information needed to make a decision in an accessible format is key to develop an effective support relationship respecting the rights, will and preferences of the person. This is especially true for people with high support needs, who may find it difficult to express themselves and communicate their needs.

→ **Service providers should be able to recognise that all forms of communication are valid and that one's ability to make decisions shouldn't be questioned based on how one communicates.** The use of alternative and augmentative communication techniques and of methodologies such as Active Support, Positive Behavioural

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Support, and Alternative and Augmentative Communication Systems¹⁰ can be particularly helpful to empower people with disabilities, especially those with high support needs, in expressing their wishes and preferences.

4. Ensuring the continuous upskilling and reskilling of the workforce

Having a well-trained care and support workforce is key to ensuring the continued development and application of support services, which contribute to the full implementation of the UNCRPD. Training on human rights principles and approaches can ensure that institutionalisation practices are discontinued in services and, therefore, support a shift towards more person-centred and community-based forms of support that can promote the full restoration of power to persons with disabilities over their own lives.

➔ **The upskilling and reskilling of professionals should be among the key priorities of a service.** Service providers should be offered training opportunities and be equipped with the right skills and tools to provide person-centred services that are in line with the UNCRPD. Some promising examples of trainings that are easily accessible to any support professional and at no cost are presented in the table below.

STEPS - Sharing The European Pathways
STEPS is a European project funded by the Erasmus + programme whose main objective was to support the deinstitutionalisation process for people with disabilities and all the actors involved in it: people with disabilities preparing to move out from institutions, those who have moved out, their families and friends, the staff working in care and support services. Within the framework of the project, training materials addressed to these different stakeholders and aimed at helping them face the transition were developed. All the materials are freely available and accessible in English, Hungarian, Finnish and Romanian at this link: STEPS (Sharing The European Pathways) .
WHO Quality Rights training
WHO has developed materials and an interactive online training to build capacity on how to improve the quality of care and support in mental health and social services and to promote the human rights of people with psychosocial, intellectual or cognitive disabilities throughout the world. Legal capacity and the right to decide, supported decision-making and advance planning are within the core trainings of this initiative.
European Care Certificate
The European Care Certificate (ECC) is a Europe-wide qualification that has been developed to cover the basic knowledge that is required for an individual to work in a health and social care setting. The ECC is aimed at trainers, employers, and staff in the sector and was developed by the European Association of Service providers for Persons with Disabilities in partnership with organisations active in the social sector from 17 European countries. The ECC is based on the rights, inclusion, choice and independence of people with disabilities and supports the human rights model of care and support provision, following the principles of the United Nations Convention.
SMARTS - Supporting Me About Rights to Sexuality
SMARTS is a 3-year project funded by the Erasmus + programme which, among its main objectives, aimed to develop the skills of care providers to make supported decisions in the field of sexuality for people with intellectual disabilities and/or mental health conditions. To this end, within the framework of the project, a training course for caregivers was developed. The course was designed to equip experienced trainers on the general supported decision-making approach embedded in the Convention on the Rights of Persons with Disabilities on one hand, and, on the other hand, on the specific use of supported decision-making process to specifically address situations and context in which sexuality is involved.

¹⁰ Examples of promising practices and communication tools that can be used to support people with intellectual disabilities in enjoying their right to legal capacity can be found here: <https://knowledgehub.easpd.eu/local/dlotcms/resources.php?id=620>.

Training to social workers working in community-based services

The [training](#) was developed in the framework of the DI Greece project, funded by DG REFORM and providing technical assistance to the Greek Ministry of Labour and Social Affairs for the transition from institutional to community-based care. The training was meant to trigger a change of approach in the social workers and other professionals by embedding principles of inclusion, participation, empowerment, and individualisation. The objective of the training was to help the development of support services that can respond adequately to the needs of persons with disabilities, vulnerable children, elderly, and their family members.

Table 4: Examples of trainings for service providers

5. Providing training opportunities and support to families of people with disabilities and staff working in mainstream services

Having a well-trained social care workforce is particularly important also because care workers can provide a crucial support to people with disabilities themselves, their families and the staff working in mainstream services in understanding the right to legal capacity and how this should be implemented through supported decision-making in everyday life.

- ➔ **People with disabilities should be trained to get ready for decision-making support and be empowered to play the leading role in the exercise of their right to legal capacity.** Trainings must include different topics, such as the right to exercise legal capacity; the right to have accessible communication and reasonable accommodations in said exercise; the right to designate and use supports according to their will and preferences at each stage of the decision-making process, from the design and approval of a support plan, the appointment of support persons, the actions of support persons, until the modification or termination of the support; and the right to complain and to resort to justice in the event of any abuse, undue influence or non-compliance by the support person(s).
- ➔ **Training opportunities should be also offered to families of people with disabilities, as they can play a key role in supporting the exercise of legal capacity.** At the same time, they can also represent a barrier to realising will and preferences. As a matter of fact, the *de facto* guardianship and informal substituted decision-making are usually perpetrated by families. Providing them with adequate tools and support to be able to understand and safeguard the rights of the person to make his/her own decisions, while also minimising risk to themselves, is therefore essential. As key facilitators of rights for the person, service providers can meaningfully contribute to empowering family members in this regard.
- ➔ Service providers can also play an important role in **supporting the staff working in mainstream services in better understanding and realising people's rights to legal capacity.** Mainstream services cover a lot of areas of life: from education to employment, from the judicial system to the healthcare system. The lack of awareness and knowledge on supported decision-making of people working in these services often constitutes a serious impediment to the exercise of legal capacity of people with disabilities in all those areas. Trainings and awareness-raising campaigns would therefore be key to tackle this issue and ensure that people with disabilities can have full control over their lives, that their autonomy and dignity is respected and that they are able to actively participate and be fully included in society like any other person.