



Implementing supported decision-making

Developments across Europe and the role of National Human Rights Institutions

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Foreword

UN Special Rapporteur on the Rights of Persons with Disabilities

Throughout history, persons with disabilities have not been recognized as subjects of the same rights and obligations as everybody else. Many have been deprived of the exercise of their rights based on assumptions of their lack of capacity to understand or to perform certain acts, and more deeply based on the poor social understanding of the diverse ways in which humanity manifests itself. As a result, legal systems all around the world have systematically restricted persons with disabilities from exercising their legal capacity, often by putting them under substitute decision-making regimes such as guardianship or curatorship. While this practice has been justified as necessary to protect persons with disabilities and society, it has proved the contrary; it renders them completely defenseless, takes away the control over their lives and reduces their opportunities to participate and contribute in society.

Persons with disabilities under guardianship, for example, lose their capacity to exercise their rights, such as voting, parenting, giving consent to medical treatment, including invasive procedures, deciding where and with whom to live, signing a work contract, opening a bank account or marrying. Substitute decision-making regimes perpetuate discrimination and exclusion against persons with disabilities, limit every aspect of their lives, and legitimize harmful practices, such as coercion, institutionalization and forced sterilization.

The Convention on the Rights of Persons with Disabilities (CRPD) openly challenged those regimes; it introduced a paradigm shift, moving away from such medical, paternalistic and ableist approaches towards a human rights-based approach. Its Article 12 enshrines the universal recognition of legal capacity in all areas of life and the provision of the support and safeguards needed to exercise it. The Convention considers all persons with disabilities as equal rights holders, providing them with the freedom and opportunity to learn from their mistakes and to live the lives they value, just as anyone else. Accordingly, all forms of substitute decision-making are prohibited under the Convention.

Since the adoption of the CRPD, several countries have started or completed legal reforms concerning the right to the legal capacity of persons with disabilities. In Latin America, Costa Rica, Peru, and Colombia have recognized the legal capacity of persons with disabilities, removed restrictions to their rights, and provided support to allow them to take their own decisions. In Europe, the report identifies significant efforts to remove legal barriers preventing the full enjoyment of all human rights by people with disabilities, although it is worth noting that challenges remain and still several legal frameworks include some degree of substitute decision-making schemes.

A legal reform consistent with the CRPD must recognize the right of all persons with disabilities to exercise their legal capacity as everybody else, and provide them with access to the support they may require to take their own decisions. It should also consider the abolishment of laws, regulations and practices that restrict the legal capacity of persons with disabilities and/or allow for substituted decision-making, such as plenary and partial guardianship, and mental health laws that allow coercive measures.

Additionally, several States are testing and implementing different models of supported decision-making, which reveal a progressive but clear paradigm shift. Supported decision-making can take many forms, including, among others, formal and informal networks, support agreements, support networks, peer and self-support groups, support for self-advocacy, independent advocacy and advance directives. As the report shows, many models in Europe have used a community-based approach for supporting persons with disabilities in specific matters such as housing, legal proceedings, medical treatments, or everyday activities.

Within the framework of the CRPD and the 2030 Agenda for Sustainable Development, the present report is an important tool to provide further clarity and raise awareness on supported decision-making and its key elements. The compendium reflects advances in the recognition of the right to legal capacity in certain legal frameworks, as well as in extra-legal and complementary initiatives, often carried out by NGOs, organizations of persons with disabilities and other actors at the grass-root level. It provides examples on how supported decision-making could be implemented and scaled up across Europe and elaborates on relevant challenges present in the region to move forward from substitute decision-making to supported decision-making.

Furthermore, the report highlights how the European National Human Rights Institutions (NHRIs) can support the shift towards supported decision-making in alignment with Article 12 of the Convention. The document stresses the important role of NHRIs for monitoring and reporting human rights violations against those under guardianship or de facto deprived of their legal capacity, as well as for investigating closed settings where persons with disabilities are often placed against their will or with the consent of guardians or legal representatives. NHRIs can also handle complaints, submit recommendations to national authorities, challenge legal provisions before courts, and undertake awareness-raising activities.

To sum up, the report gives us an opportunity to understand how supported decision-making works in practice and is a tool that could support efforts to build the capacity of key stakeholders, including legislators and policymakers, NHRIs, civil society and organizations of persons with disabilities, on article 12 of the CRPD. It confirms that other responses are possible; that it is feasible to support persons with disabilities to exercise their legal capacity instead of resorting to restrictions to this right due to the lack of adequate support. In doing so the report invites us to revise the legal and policy frameworks that continue to discriminate against persons with disabilities. Needless to

say, all efforts in this direction must have as point of departure the active consultation and involvement with/of persons with disabilities and their representative organizations.

Let's use this report to bring us closer to achieving equal recognition before the law for all persons with disabilities in Europe, let's move towards supported decision-making regimes firmly based in the Convention on the Rights of Persons with Disabilities.

Ms Catalina Devandas-Aguilar

UN Special Rapporteur on the Rights of Persons with Disabilities

1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (the “Convention”) came into force more than ten years ago and has been ratified by all European Union Member States (MS) and the European Union (EU) itself. The Convention reflects a paradigm shift from a medical approach to a rights-based approach, where equality should be at the centre of legislation, policies and practices affecting persons with disabilities. This is made clear from the outset of the Convention, which states that its purpose is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.

As guiding principles of the Convention, inherent dignity, individual autonomy, including the freedom to make one’s own choices, and independence of persons are reflected throughout the text. Article 12 of the Convention is premised on these general principles and operationalises them by setting out that States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life (this has been referred to as the “right to legal capacity”). From a human rights perspective, legal capacity - the right to make choices and be recognised before the law – is key to ensuring autonomy and inclusion for persons with disabilities, as well as equal dignity.

Throughout history, many groups have been denied their legal capacity. Among them, persons with psychosocial disabilities, as well as persons with intellectual disabilities, autistic persons and persons with dementia (also called “cognitive disabilities”) are particularly affected.¹ In practice, the legal capacity of many persons with psychosocial disabilities is either completely removed or substantially limited and, consequently, they are placed under partial or plenary guardianship.² Being denied legal capacity can mean not being allowed the right to make decisions in many aspects of life. This can negatively impact on a whole host of civil, political, economic, social and cultural rights.

Article 12(3) of the Convention requires States Parties to move away from “substitute decision-making regimes”, like guardianship, towards arrangements that guarantee that persons with disabilities have the support they need to make their own decisions and enjoy their rights (“supported decision-making”). This paradigm shift should be at the heart of States’ considerations when respecting the right to legal capacity.³

The UN CRPD Committee, composed of independent experts appointed to monitor the implementation of the Convention and assist on its interpretation, has called on states to “review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by

supported decision-making, which respects the person's autonomy, will and preferences."⁴ As for the European Union, the Committee recommended it to "step up efforts to foster research, data collection and exchange of good practices on supported decision-making, in consultation with representative organizations of persons with disabilities".⁵

A Resolution on Mental Health and Human Rights by the United Nations Human Rights Council also calls upon States to "abandon all practices which fail to respect the rights, will and preferences of all persons, on an equal basis" with others and to "provide mental health services for persons with mental health conditions or psychosocial disabilities on the same basis as to those without disabilities, including on the basis of free and informed consent".⁶

2. Objectives and methodology

Ensuring autonomy and putting systems of supported decision-making in effect is a major undertaking for many European states. In implementing its obligations under the Convention, states find it challenging to identify how this could be done in practice. In addition, as the European Court of Human Rights (ECtHR) has not yet aligned its jurisprudence with the CRPD, this creates additional difficulties for states to fully implement supported decision-making. Other actors, such as civil society organisations (CSOs), disabled persons organisations (DPOs) and National Human Rights Institutions (NHRIs), are working to demonstrate that a rights-compliance legislation, policy and practice is possible.

In order to support the collection of good practices, the European Network of National Human Rights Institutions (ENNHRI) and Mental Health Europe (MHE) consulted their members on existing supported decision-making models and practices in their respective countries. In addition, a literature review was conducted by members of ENNHRI's CRPD Working Group (WG) in order to take stock of other examples, initiatives and approaches.

This compendium aims to provide examples on how supported decision-making is being advanced across Europe, in light of the Convention and the guiding interpretation from key regional and international actors. The examples have a particular, but not exclusive, focus on supported decision-making for persons with psychosocial disabilities. They do not aim to be exhaustive but are collected to support states as well as other actors in the disability field, such as NHRIs, to consider new ways of working towards support-decision making, inspired by the paradigm shift of the Convention.

Concretely, the objectives of this report are:

- To provide further clarity and raise awareness on what supported decision-making entails in theory and practice;
- To identify core elements of promising practices by examining common elements emerging from national examples;
- To better understand how NHRIs can contribute to the shift towards supported decision-making and compliance with Article 12 of the Convention.

This report begins with a short account of what stakeholders consider to be key elements of supported decision-making. The following section then highlights some emerging practices across Europe, which are divided between legal and extra-legal initiatives. In the last section, we describe what NHRIs can do to contribute to the shift towards supported decision-making.

3. Supported decision-making from theory to practice

The provisions of the Convention, alongside the General Comments by the UN CRPD Committee, provide guidance on what supported decision-making measures should look like and more specifically on the safeguards that should apply to such measures. In interpreting and understanding how supported-decision making can be implemented in practice, the views of relevant stakeholders, such as international and regional human rights bodies, as well as academics, are instrumental. Persons with disabilities and DPOs should also be able to participate fully and effectively in the legislative and policy discussion regarding supported decision-making.⁷

In a previous position paper, MHE provided guidance to stakeholders, such as European states and the EU, on what legal capacity means to persons with psychosocial disabilities and how they can be supported to make decisions for themselves.⁸ A literature review conducted by ENNHRI added to this work.

Even though there is no universally accepted model of supported decision-making, several elements pertaining to supported decision-making seem to be crystallising as “guiding principles” in the disability advocacy field and academic literature.

- Stakeholders emphasise that **adherence to human rights and international law** is one of the fundamental characteristics of any supported decision-making regime.⁹ Respect for the full range of human rights, including the right to privacy, needs to be guaranteed when implementing such regimes.
- To ensure the autonomy of persons with disabilities, the **will and preferences** of the person supported shall prevail over an external assessment of their best interests.¹⁰ Any support provided to the person should respect the person as an active agent and an autonomous bearer of rights. It needs to maintain the person’s right to legal capacity and to make decisions which have legal effect. Any support provided to persons with disabilities shall not jeopardise his or her individual autonomy and, in practice, shall not amount to substituted decision-making.
- **Free choice**, including the person’s right to refuse support, is a core element of supported decision-making and includes that the person can terminate or alter the support at any time.¹¹
- Free choice of support also requires that the person, in order to give informed consent to or explicitly apply for the support measure, receives **correct and accessible information**. The information should among others include the aim, extent and practical details of support. Information needs to be provided in a way that the person can understand and in a place they can access. This is often

referred to as the “honesty and clarity” elements of supported decision-making.¹²

- Any support regime should be **flexible**, meaning that it has to be able to provide tailored solutions to the challenges of the person while also respecting and being responsive to evolving circumstances of the person concerned.¹³
- Since decision-making support is a voluntary instrument, states have a positive obligation to make it a reality in practice. Voluntariness requires **supported decision-making to be available** to all who would require it. The state is required to make supported decision-making available (free of charge or at a symbolic cost), irrespective of the support needs of the person.¹⁴
- **Absence of undue influence** and conflict of interest is a vital safeguard in providing adequate support.¹⁵ In this regard, a third party needs to be able to verify who the support person is and to challenge the actions of the support person if he/she is acting contrary to the will and preference of the person with support needs. This element of supported decision-making can be understood in conjunction with the element of **family involvement**, as family members often serve as the closest support of the person concerned.¹⁶ They may also play a crucial role in supervising the support measure, ensuring that the rights and autonomy of the supported person are being respected.
- States must adopt a **community-based approach** to the provision of decision-making 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.¹⁷
- Supported decision-making needs to be **subject to regular review** by a competent, independent and impartial body or the judiciary. In this regard, access to justice for persons with disabilities needs to be ensured, included through adequate legal representation and a system that accommodates the needs of the person concerned.
- Some also identify “**risk taking**” as an element of supported decision-making.¹⁸ The support paradigm of the Convention requires a delicate balance between adequate support and respect for human dignity, leaving room for the person to exercise choice and express his or her personality. This means that the “dignity of risk” needs to be accepted, which entails placing greater value on the individual’s right to decide even when decisions seem unreasonable or risky to others.¹⁹

In addition to the elements above, the UN CRPD Committee as well as the UN Special Rapporteur on the Rights of Persons with Disabilities also gave more information about what forms supported decision-making can take and noted that such support could be of varying types and intensity, including informal and formal arrangements.²⁰ For example:

- support networks, support agreements, peer and self-support groups, support for self-advocacy, and independent advocacy,
- the provision by banks of information in understandable formats which enable persons with disabilities, to open accounts, enter into contracts or conduct transactions,
- advanced planning, which can be particularly helpful for persons with psychosocial disabilities who may experience crisis situations and whose doctors, family member and friends could benefit from prepared guidance that outlines the person's will and preferences.

4. Advances towards supported decision-making

Across Europe, several practices are emerging which aim to implement the transition towards supported decision-making. Not all practices fulfil the entirety of the key elements identified above - some of them may be fully aligned with one of the principles, but lack in implementing another. In this section we set out some developments in Europe and distinguish between legal frameworks and extra-legal initiatives.

A. Legal frameworks

The legal frameworks set out below are considered as advances as they underline the importance of supported decision-making. However, all countries in Europe still include some type of substitute decision-making schemes as a last resort. This means that, in many cases, where there is a choice between the two, substitute decision-making prevails over supported decision-making, which is problematic in view of compliance with the Convention. In addition, the UN CRPD Committee regularly reiterates that reforms that alter, but do not abolish, substitute decision-making continue to be in conflict with the Convention.²¹

It is important to note as well that, while a legal framework can be positive in theory, very often it is not followed up by proper implementation and/or usage in practice.

Austria

In Austria, a new legislation called the Second Protection of Adults Act entered into force on 1 July 2018.²² The Act is guided by the principles of autonomy, self-determination and decision-making guidance. It foresees four mechanisms in case a person is limited in its decision-making abilities but none of these mechanisms results in the automatic loss of legal capacity. The law prescribes for the use of enduring powers of attorney, which enables a person to appoint a representative for the event that they lose ability to make decisions in the future. As a measure of last resort, a court can decide to appoint a representative or substituted decision-maker. This can only be done, however, after examining each individual's specific circumstances and restricting the representation to a particular matter and for a specific time. Finally, certain decisions cannot be decided by a representative at all, such as making a will or an advance healthcare directive (Patientenverfügung), setting up an enduring power of attorney, getting married, adopting a child or acknowledging paternity.

Belgium

In Belgium, a law of March 2013 was enacted with the goal²³ First, the law provides that a person can indicate their preference for an administrator and/or 'person of trust', would their legal capacity be limited by a judge in the future. Second, when deciding on a person's legal capacity, judges have to pay attention to the specific situation of each person. Supported decision-making ("assistance") needs to be prioritised over substitute decision-making ("representation") and judges need to *take into account* the will and preferences of persons when deciding who to appoint as their administrator. However, a judge is not *obligated* to choose as administrator the preferred option of the persons concerned. Someone's assigned 'person of trust' can mediate between the person and his or her administrator in assisting with expressing the will of the person.

Although this law is a step forward, in practice judges often do not have sufficient time and resources to carefully assess the specific situation of each person, and mostly choose for substituted rather than supported decision-making, hereby disregarding the will and preferences of persons. Judges are also very likely to appoint a professional administrator (usually a lawyer) rather than someone in the person's family or personal network.

Czech Republic

The 2012 Civil Code, which entered into force in January 2014, contains "assistance in decision-making" within the system of support measures for adults with "diminished capacity" to act.²⁴ Other measures are: representation by a next of kin, guardianship and advanced directives. Assistance in decision-making is only intended for persons with "mental disabilities," which indicates that the legislation is based on the medical rather than social model of disability. A person can choose one or more supporters, without further specification. In practice, apart from individuals, some organisations also provide assistance.

Supporters accompany persons to legal proceedings, provide them with necessary information or advice. Furthermore, the support may affix his signature to contracts or other legal acts concluded by the person receiving assistance and they may invoke the invalidity of a legal act made by the person receiving assistance. The supporter may also be present when the person is dealing with administrative bodies and they may consult and search the administrative file together with the supported person.²⁵ The supporter also has a legal standing during the proceedings on involuntary hospitalisation or detention in social care institutions.²⁶

The assistance is based on an (oral or written) agreement authorised by the court. The scope of the assistance and the content of the agreement are up to the prospective parties. The court may only intervene (a) before the contract is concluded if it is

apparent that the interests of the assisting person are contrary to the interests of the person receiving assistance or (b) during the assistance, if the court finds out that the assisting persons are exerting improper influence or unjustly enriching themselves at the expense of the person receiving assistance.

Apart from assistance in decision-making, the law also establishes that a person with a disability may use a special type of support during involuntary hospitalisation proceedings. Although the person is represented by a legal representative (attorney), they can also choose a confidant, who can support them in the proceedings as well as exercising the procedural rights (proposing evidence, appealing against the decision, among others) on behalf of the detained person. There is no formal requirement to appoint a confidant and, at present, no information on how this measure is used in practice is available.

By the end of 2016, only 155 assistance agreements had been concluded. Persons with disabilities and their families are rather reluctant to choose this new measure as there is no comprehensive information provided by the state about the objectives and the use of the new legislation. Moreover, the follow-up legislation is yet to be adopted and the role of the assistant in many specific legal acts is still unclear. In addition, many people with disabilities (particularly those living in large institutions) do not have a close person who could provide them with qualified assistance.

Georgia

The 2015 amendment of the Civil Code in Georgia includes a reform of legal capacity provisions.²⁷ Plenary guardianship has been abolished and supported decision-making has been established. Persons, their relatives or social services, can now address the court with the request to declare them 'beneficiaries of support'. The court needs to take into account the 'the interest and will of a beneficiary of support' and mention the specific areas for which support is required. Support frameworks can be broadened or narrowed and are overseen by a supervisory body. Supporters are either individuals or government agencies.

Despite the positive steps in legislation, the shift towards supported decision-making has not yet been fully adopted by courts and implementation of the reform is deficient. Indeed, courts appoint supporters for such a wide range of rights some compare this system to a new form of guardianship.²⁸

Germany

In Germany, the Federal Government abolished statutory custodianship ("Vormundschaft") for adults in 1992. Before that, legislation allowed the formal deprivation of a person's legal capacity²⁹ While, as a rule, legal capacity is fully maintained and the legal guardians are obliged to abide by the wishes of the persons

they represent, in practice the existing supported decision making component for persons with disabilities is neglected.³⁰ The UN CRPD Committee is concerned that the current legal instrument of guardianship is still incompatible with the Convention.³¹

In the German legal system, courts appoint guardians with regard to specific areas, such as financial affairs, health or personal welfare. A guardian cannot be appointed against the free will of a person. However, courts can decide whether a person is capable of a “free will” or not; hence, the decision about the free will is crucial. It is possible to issue an advance directive on guardianship (Betreuungsverfügung) to express one’s will and preferences in certain matters beforehand; the prospective guardian will be controlled by the court. To avoid guardianship, a person can give someone of his/her choice of a power of attorney (Vorsorgevollmacht). With regard to medical treatment, one can put down her/his will and preferences in a “living will” (Patientenverfügung) which functions as a precautionary measure.

The guardian is in place to support the person concerned. The guardian may use his/her power to represent and act on behalf of the person only if it is necessary. The guardian may only refrain from acting according to the will and preferences of the person concerned if it contradicts his or her best interests. If the guardian takes a decision which is likely to affect human rights (such as matter related to medication or moving to an institution), the court has to approve the decision and should hold a hearing on the matter, with the person concerned.

Finally, although all decisions made by the guardian must take into account the will and preferences of the person concerned and shall be made as supported decision-making, resources are scarce, which makes it hard to have an individual communication about the will and preferences in every single matter.

Ireland

In 2015, the Assisted Decision-Making (Capacity Act) was adopted, replacing the Lunacy Regulation Act from 1871.³² The Act provides for three types of decision-making supports: assisted decision-making; co-decision-making and decision-making representatives. The Act also provides for enduring powers of attorney and advance healthcare directives. Each of these roles must be carried out in accordance with the will and preferences and of the person with “capacity issues”. Therefore, while the Act still allows for substitute decision-making, it also opens the possibility for implementing supported-decision (through “assisted decision-making”).

Assisted decision-making is based on an agreement between the person asking for support and one or more persons of their choice. It can relate to *personal welfare issues* including accommodation, employment, education or training, healthcare; or to *property and affairs issues* including control and management of one’s property or property rights, and conduct of proceedings before any court or tribunal.

Decision-making assistants support persons to obtain relevant information for a decision, advise them by explaining the information, ascertain the will and preferences of the persons and assist them to communicate and express a decision, endeavouring that decisions are implemented. They never make a decision on behalf of the person. Complaints can be issued if decision-making assistants act outside the scope of their functions, or use fraud, coercion or undue pressure for example.

Unfortunately, most parts of the new Act have not yet entered into force, and the foreseen Decision Support Services have not been established due to inadequate funding. In addition, significant amendments to the legislation might be introduced.³³

United Kingdom (Scotland)

The 2015 amended Mental Health (Care and Treatment) Act provides individuals with a possibility to make advance statements regarding treatment and sets out a supported decision-making instrument called "independent advocacy".³⁴ Independent advocacy can be provided by an individual or by a group of advocates and is centred around the principle of peer support.

Every person with an intellectual or psychosocial disability has a right to independent advocacy when they are detained in a hospital or subject to other forms of compulsory placement or treatment.³⁵ The person is informed about the right to independent advocacy by their social worker (mental health officer), hospital staff or the organisation that provides advocates. The role of the advocate is to ensure that the person understands their situation and decisions issued by the court, to support the person to make decisions about their care and circumstances or to speak up on their behalf. They are not allowed to give their own views or to conclude legal acts, such as contracts, on behalf of the person. They do not have an automatic right of access to the patient's medical records; however, the patient may authorise them to have such access as well as access to information regarding planning or providing patient care or treatment. They have a right to be involved in all stages of the decision-making process.

Advocates are independent from hospitals; they are employed by organisations funded by the local authority and/or National Health Service. It is a duty of the local authority to ensure that everyone in their area has access to independent advocacy (supporters) if needed. The law itself does not provide for any safeguards, but the Scottish independent advocacy alliance (SIAA) issues principles and standards to which the advocacy organisation should adhere. The local authority supervises the provision of advocacy and they may decide to discontinue the funding, if there is a breach of code of conduct or the organisation does not adhere to the standards.

According to data from the Scottish independent advocacy alliance (SIAA), during 2015-2016 approximately 30,500 people accessed advocacy in Scotland.³⁶ Still, there are

insufficient service providers and organisations call for advocates to adopt a more preventive role.³⁷

Spain (Catalonia)

Catalonia has its own legislative framework in the field of Civil Law.³⁸ The substantial reform of the Catalan Civil Code (CCC) in 2010 included an integral reform and reconceptualization of legal mechanisms available to support individuals with disabilities or with complex needs. The reform includes an instrument respectful of a person's legal capacity: the assistance mechanism.

Assistance is a modular and flexible instrument which can range from supporting persons in one aspect of their life (for example, healthcare) to a combination of several aspects (healthcare and financial management as well as bureaucratic, administrative or legal proceedings). The most important characteristic of assistance is that it is not linked to the previous absence or limitation of a person's legal capacity. Assistance can only be initiated by the person who demands support and respects the wishes and preferences of the person. An assistant can be a physical person (family member, relative or friend) but also a legal person, such as organisations complying with the requisites established by the Catalan Government. The government finances such services and assistants are subject to public control and supervised by the court authority on a yearly basis. Assistance cannot interfere on highly personal rights such as the right to get married, inherit or draft a will or the right to vote. Assistance can be terminated whenever the person enjoying support decides for it.

Assistance is increasingly used to avoid the deprivation of legal capacity and the use of substituted decision-making mechanisms. Since 2016, the number of assistances has overtaken the number of court-appointed guardians. No public data is available regarding the number of individuals who have formally requested an assistance but, as of 30 June 2019, 124 active assistances are accounted from which 70 are provided by the organisation SUPPORT.³⁹

B. Extra-legal initiatives

Extra-legal initiatives are often initiated and carried out by non-governmental organisations (NGOs), DPOs and other actors on a grass-root level. These range from support for specific matters such as voting, housing, legal proceedings or medical treatments, to support in everyday activities. The grass-root work of organisations does not substitute the importance of legal reforms nor does it exempt States as main duty bearers, but it is an essential complement to the implementation of supported decision-making in practice.

Finland

The Open Dialogue model is a practice originally developed in Finland in which care decisions are made with the personal input of the individual concerned, together with wider networks of their choice. The approach is based on support in people's homes and communities. Service providers aim to facilitate regular 'network meetings' between the person and his/her choice of an immediate network of friends, carers or family, and members of the healthcare team. A strong emphasis is placed on transparency in treatment planning, and decision-making processes aim to respect a person's will and preferences, safeguarded from undue influence. Such support enables the person to retain their legal capacity and to make the final decision on, for example, his/her treatment, after exchanges and reflection within the group.⁴⁰

Germany

The new Federal Law on Participation (Bundesteilhabegesetz) entered into force on January 2017 and promotes the establishment of independent participation counselling centres across the country.⁴¹ The Complementary Independent Participation Advisory Service (EUTB) is a counselling centre for persons with disabilities or their relatives. The free consultations take place individually and are adapted to the needs and possibilities of the person seeking advice. The focus of the EUTB is on peer counselling, which means that the counsellors themselves are experts by experience, and usually deal with questions regarding social benefits. Counsellors do not tell people what to do but listen to their needs, report their own experiences, explore possibilities and resources, and support them to find their own solutions. For now, there are about 500 centres all over the country.

Greece

A 2015-2016 project called 'Action Platform for Rights in Mental Health' aimed to support the rights of persons with mental health problems and bring about change in the way they are perceived.⁴² It set up the first Advocacy Office in Greece, which dealt with 319 cases in close collaboration with key actors in the field of advocacy, such as the

Greek Ombudsman. The Office offered individualised support together with lawyers and clinicians. The main services included information, consultation, guidance and referral to other services and institutional bodies to users of mental health services. It worked closely with representative users' and families' associations, aiming to empower people to claim their rights and make their own decisions on their way to recovery.

Spain (Andalusia)

Since 2016, the Andalusian Health System has launched a document with an accompanying Guide for advance care planning in mental health.⁴³ It has been developed by the Andalusian Task Force on Human Rights and Mental Health Care, which includes users, professionals, service providers and families. The aim is to promote the autonomy of persons with psychosocial disabilities and support people in their decision-making. Users can complete a document explaining symptoms they usually notice when entering in a crisis situation, what makes them feel good and bad when experiencing distress, who their contact person is, who they would allow to visit, the type of care they prefer in case of crises, persons who can take decisions for them, information about their general health, diet etc. This is then included in their medical record and made available to health professionals when they are unable to fully express their wishes and decisions.

Sweden

The Swedish Personal Ombudsman Programme is a programme that supports decision-making for persons with severe mental or psychosocial disabilities, through the appointment of "personal ombudsmen" (PO).⁴⁴ Initially, ten projects were financed and since the year 2000, the PO system has been expanded to the whole country and PO is now a social profession receiving permanent funding.⁴⁵ The PO is a professional who works full-time for the interests of their clients and does only the person receiving support wishes. PO's must adjust to their clients and be very flexible, creative and unconventional in finding ways to work with persons with mental health problems. They must make up flexible working-schemes every week according to the wishes of their clients. The PO should be able to support clients in all kind of matters ranging from family-matters to housing, accessing services or employment, and be well-skilled to be able to argue effectively for the client's rights in front of various authorities or in court. The support can be stopped at any time at the request of the assisted person. The PO has been recommended by the UN CPRD Committee as a supported decision-making programme specifically useful for persons with psychosocial disabilities.⁴⁶

Other extra-legal initiatives

In **the Czech Republic**, Skok do života, an organisation from the Hradec Králové Region provides, among others, 'professional support' for persons with intellectual or psychosocial disabilities since 2014.⁴⁷ Apart from providing direct support, they have

developed several guidelines and other materials for supporters and work on raising awareness among the general public on the use of supported decision making.

The **German** project Experienced-Involvement (Ex In) aims to promote autonomy and self-determination by offering support to persons who are in psychiatric hospitals from persons with lived experience.⁴⁸

In **Ireland**, various groups such as Sage Advocacy, Inclusion Ireland and the National Advocacy Service provide support and advocacy in health care and social services for vulnerable adults, older persons and persons with healthcare needs.⁴⁹ For example, they support people to return from hospitals and nursing facilities to their homes, in accordance with their wishes and provide advocacy services for adequate home care. They also work to enable people to live and die in the place of their choice, and support those who have complaints about healthcare services.

Various groups in the **Netherlands** support individuals in making their own decisions. The initiative Eigen Kracht Centrale brings together persons and their relatives to enable them to reach decisions independently.⁵⁰ They offer tailored professional information regarding their problems and what would be the appropriate services. This reflects a shift in decision-making compared to traditional governmental interventions.

The **Romanian** foundation "Pentru voi" in Timișoara works with 66 persons under judicial interdiction (persons who are not able to exercise their legal capacity), of which 6 persons have the foundation "Pentru voi" as a legal guardian.⁵¹ The objective is that all decisions are made by the persons themselves with the assistance of staff members and their legal representatives, who provide explanations via various means of communication adapted to each person's needs.

The Mental Health Network (Greater Glasgow) in **Scotland** is a peer support organisation that assists people to make Advance Statements that will be effective in practice.⁵² These can include personal statements setting out the person's wishes for matters going beyond medical treatment, such as caring responsibilities, pets and bills.

5. The role of NHRIs in the shift towards supported decision-making

National Human Rights Institutions (NHRIs) are State bodies, independent from government, with a broad mandate to promote and protect human rights, including the rights of persons with disabilities. Many NHRIs have been designated as the independent monitoring mechanism under Article 33(2) of the UN CRPD to promote, protect and monitor the implementation of the Convention. As made explicit under that Article, when designating or establishing such a mechanism, States Parties shall consider the UN Paris Principles relating to the status and functioning of NHRIs. Even where NHRIs do not have this formal mandate, they make use of their functions to ensure that persons with disabilities can enjoy their rights on an equal basis with others.

As a response to legislations and practices throughout Europe that are in violation of the right of persons with disabilities to enjoy legal capacity in all aspects of life, European NHRIs have made use of their various functions to promote and protect this right⁵³ The UN Special Rapporteur on the Rights of Persons of Disabilities has also raised the importance of NHRIs' work to carry out inquiries and investigations in relation to the enjoyment of the right to legal capacity of persons with disabilities.⁵⁴

In order to better understand how NHRIs can contribute to the shift towards supported decision-making and compliance with Article 12 CRPD, this report highlights concrete examples from European NHRIs. The examples are non-exhaustive, but illustrative of the central role that issues related to legal capacity play in NHRIs' work in the field of disability rights.

A. Monitoring and reporting to national and international actors

Human rights monitoring is a crucial task of NHRIs, through which they gather, verify and use information to address human rights violations. By acting as human rights watchdogs, NHRIs' independent monitoring allows them to assess whether international human rights standards are met at the national level, through domestic legislation, policy and practice.

With reference to international legal standards, including Article 12 of the Convention, European NHRIs have regularly assessed if persons with disabilities can enjoy their right to legal capacity in all aspects of life. This monitoring exercise is carried out, for example, through the review of legislations (such as those allowing for full or partial deprivation of legal capacity), learning from the experience of persons with disabilities and working alongside them to identify human rights issues, gathering relevant data (such as statistics on the number of people under guardianship), or consulting disabled

persons organisations. NHRIs also use indicators to guide their monitoring, assessment and reporting.⁵⁵

For example, the **Georgian NHRI** (Public Defender of Georgia) published an extensive report on legal capacity, as a result of its monitoring of the practical implementation of earlier legislative reforms aiming at establishing an institution for rendering support to persons with disabilities in their decision-making process, contrary to plenary guardianship.⁵⁶ The NHRI found that, despite positive elements in the legislative reform, substantial deficiencies in its implementation allowed for the conclusion that the right to legal capacity of persons with disabilities was still violated in practice. Based on its monitoring exercise, the Georgian NHRI submitted recommendations to state agencies to improve their policies and practices, which are necessary to effectively implement the new legislative provisions. The NHRI continues to follow these developments.

Similarly, the **Dutch NHRI** (Netherlands Institute for Human Rights) commissioned a study on the conformity of Dutch legislation with Article 12 of the Convention. The study was the basis for a discussion organised by the Dutch NHRI on whether there is a need for reform in the current system of guardianships in the Netherlands.⁵⁷

The **Cypriot NHRI** (Commissioner for Administration and Protection of Human Rights), through a special report, also monitored the reality faced by persons with disabilities in Cyprus and drew recommendations to the relevant ministries on the minimum safeguards that must be complied with to achieve legislation and regulations that are compliant with Article 12 of the Convention.⁵⁸

NHRIs also use their monitoring to inform relevant international actors, such as the UN CRPD Committee, on the state of play of the Convention's implementation at national level. Issues related to legal capacity, guardianship systems and supported-decision making have figured predominantly on NHRIs' reporting.

B. Advising government and parliament

NHRIs have privileged access to national authorities because of their special status as state bodies. They use this powerful mandate to submit targeted recommendations to national authorities, through meetings with relevant Ministries, issuing declarations and publishing press releases. They can also address the Parliament on relevant human rights issues and many are routinely asked to provide their opinions on draft legislations.

For instance, the **Irish NHRI** (Irish Human Rights and Equality Commission) submitted various observations on the draft legislation on mental capacity, many of which were incorporated into the final bills.⁵⁹ The **Scottish NHRI** (Scottish Human Rights Commission) has also repeatedly called for a comprehensive review of the framework regarding non-consensual care and treatment to reflect supported decision-making.⁶⁰

This led to an announcement in March 2019 of a review of relevant legislation governing mental health and legal capacity, which also aims to address supported decision-making.

The **Azerbaijani NHRI** (Commissioner for Human Rights, Ombudsman) also proposed numerous amendments to the draft Law on Psychiatric Assistance and on Psychological Assistance, which were reflected in the adopted text.

In 2019, the **Serbian NHRI** (Protector of Citizens) issued an Opinion on the “Draft Law on the Protection of the Rights of Persons with Mental Disabilities and users of the Accommodational Social Services”, stating, among other issues, that the protection of rights of persons with disabilities requires a systematic approach and inter-ministerial cooperation, with the objective of achieving their independent living in the community and enacting systems for supported decision-making.⁶¹ In 2020, the NHRI raised several issues and recommendations regarding legal capacity in its “Opinion on the Proposal of the National Strategy for Improving the Position of Persons with Disabilities in the Republic of Serbia for the Period from 2020 to 2024”, again focused on the need to abolish substitute decision-making and to move towards a supported decision making system.⁶²

Since 2010, the **Georgian NHRI** has criticised the system for legal capacity in the country in its Parliamentary Reports, proposing recommendations of reform to state agencies and Parliament. Due to its continuous campaigning, the Georgian NHRI was included in the Working Group established to propose a reform in the system for legal capacity, even before a first draft was presented to Parliament. While a legislative reform was indeed carried out in 2015, the NHRI has continued to follow the issue to monitor the implementation of the reform in practice.⁶³

Other NHRIs have also been involved in the assessment of legislative compliance of new mental health legislation, such as in **Belgium** (Unia, the Interfederal Centre for Equal Opportunities) and the **Albanian NHRI** (People’s Advocate).⁶⁴

C. Investigating facilities and handling complaints

In addition to its broad monitoring mandate, some NHRIs are legally vested with strong investigative powers, including to monitor places where persons with disabilities are deprived of their liberty, such as mental health facilities, prisons, institutions and psychiatric wards. This allows NHRIs to identify violations of the rights of persons with disabilities, including in relation to Article 12 of the Convention.

The UN Special Rapporteur on the Rights of Persons with Disabilities has recommended States to ensure that NHRIs “be mandated to carry out inquiries and investigations in relation to the enjoyment of the right to legal capacity of persons with disabilities and provide assistance to persons with disabilities in accessing legal remedies”.⁶⁵

Some NHRIs can also receive and handle individual complaints of alleged human rights violations. They then issue non-binding recommendations to relevant national authorities seeking to terminate or redress the violation of rights. Where NHRIs handle individual complaints, this mandate is accompanied by an obligation of other authorities to pay due regard to the views of the NHRI. Many European NHRIs have received complaints from or on behalf of persons with disabilities about violations of their right to legal capacity.

Among others, the **Albanian NHRI** (People's Advocate of Albania) and the **Georgian NHRI** have monitored mental health institutions and issued recommendations to relevant authorities to address potential violations.⁶⁶ The **Serbian NHRI**, for instance, acting as the National Preventive Mechanism (NPM), addressed the National Assembly to call for enhanced measures to protect persons with psychosocial disabilities, the revision of provisions governing medical consent and the need to amend legislation to ensure supported decision-making.⁶⁷

D. Legal interventions and proceedings

Some NHRIs are also vested with strong legal powers, such as being able to challenge legal provisions before administrative and/or constitutional courts, to join court proceedings as third parties at the national and regional levels, and to represent victims of human rights violations before courts. The legally-binding nature of court decisions make this a valuable instrument for persons with disabilities, which have relied on European NHRIs to bring individual and systematic issues related to legal capacity before courts.

For example, the **Irish NHRI** has acted as *amicus curiae* on a case focused on what it means to be a "voluntary patient" in a psychiatric hospital. As an outcome, the Irish Court of Appeal noted that "voluntarism remains a cornerstone of our system of medical treatment", in light with the reasoning put forward by the NHRI.⁶⁸ In a different case, the NHRI assisted the Irish Supreme Court, which ruled on the lawfulness of the procedures under which someone can be kept in a hospital or nursing home, and made a ward of court. The outcome of the case was welcomed by the NHRI, which found it to have "significant implications for the rights and protections afforded to people whose ability to make significant life decisions may be questioned, including their right to have their voices heard and to be afforded the dignity of being consulted on decisions which impact their lives".⁶⁹ The NHRI also intervened in a case regarding the right of a man detained in a psychiatric institution to initiate a review of his detention.⁷⁰

Similarly, in 2016 the **German NHRI** (German Institute for Human Rights) submitted an *amicus curiae* intervention in a procedure before the Constitutional Court of Germany

regarding the exclusion of persons with disabilities from voting in elections. The Court reached its decisions in 2019, safeguarding the right to vote for persons with disabilities.⁷¹

The **Danish NHRI** (Danish Institute for Human Rights) intervened in a case before the national courts, which reached the Danish Supreme Court, regarding persons with disabilities who were under a specific system of guardianship that made it impossible for them to vote in national parliamentary elections and referenda.⁷² In January 2019, the Supreme Court ruled that this practice did not lead to any human rights violation, a decision which is now being challenged by the applicants before the European Court of Human Rights (ECtHR).

European NHRIs, through ENNHRI, have submitted a third-party intervention before the European Court of Human Rights regarding this case, relying on international standards (including Article 12 CRPD) and the growing European consensus around the principle that the right to vote for persons with disabilities shall be the rule and that persons with disabilities should not be deprived of this right based on their disability.⁷³

E. Promoting the shift towards supported decision-making

NHRIs can also act as multipliers of messages in support of the shift towards supported decision-making and work for a better understanding – from State authorities, society, health and legal professionals, among others – of international standards and how new systems can and should be introduced to better protect the right to legal capacity of persons with disabilities.

NHRIs undertake awareness-raising activities (such as campaigns, publications, making use of social and traditional medias), cooperate with academia and schools, engage with local and regional authorities, and facilitate dialogues between state authorities and people with disabilities about human rights and legal capacity.

For example, the **Serbian NHRI** organised a conference on "The right to make a decision - the issue of deprivation of the legal capacity of persons with disabilities in Serbia" with the aim of pointing out widespread practice and serious violation of the rights of people with disabilities due to deprivation of capacity, and launching an initiative to change this approach.⁷⁴

The **Irish NHRI** has launched a national awareness-raising campaign called "Because we're all human. Means we're all equal" aimed at informing attitudes towards people with disabilities. It features thirteen people from across Ireland sharing their experiences of living with autism, an intellectual disability or complex needs; being visually-impaired or blind, hard of hearing or Deaf; and having a physical disability or being affected by mental ill-health.⁷⁵

In 2016, the **Cypriot NHRI** launched a campaign to promote the right to vote for persons with disabilities, in accordance with Article 12 of the Convention. The campaign included sending printed information material to inform all election centres, political parties, organisations of people with disabilities and other authorities. The NHRI also informed the public through printed and social media.⁷⁶

The **Belgian Interfederal Centre for Equal Opportunities** (Unia) also carried out an awareness-raising campaign focused on supporting the empowerment of persons with disabilities to make their own decisions. It included printed posters and an online video.⁷⁷

European NHRIs, for instance the **German NHRI**, also organise conferences and trainings about the UN CRPD for judges and judicial officers.

F. Working alongside persons with disabilities and disabled persons organisations (DPOs)

The active and informed participation of persons with disabilities in decisions that affect their lives and rights is at the very core of the Convention, and is essential part of a human rights-based approach in decision-making processes.⁷⁸ European NHRIs rely on this principle when using their functions to ensure that the rights of persons with disabilities are respected. They empower, consult, assist and work alongside persons with disabilities and DPOs.⁷⁹ Many NHRIs have formalised this relationship through specialised Advisory Committees.⁸⁰

There are many ways in which NHRIs can cooperate with persons with disabilities and DPOs when working for the protection of the right to legal capacity, such as regularly and meaningfully consulting them before adopting positions on matters such as guardianship systems and legal capacity, involving them in inspections and visits, organising trainings and conferences to empower them, and facilitating their access to national authorities.

5. Conclusion

More than ten years after the Convention entered into force, State Parties still need to fulfil their duty and implement supported decision-making systems for people with disabilities to receive the full recognition they deserve.

Legislative changes are planned or already being discussed across Europe (and beyond). These contain some common key components, such as the ability to issue advance statements; an emphasis on the will and preferences of a person; a requirement to exhaust support options before taking decisions on behalf of others; and the need for flexibility in every supported decision-making system.

While some progress has been made in many countries, most of national legal frameworks still draw a fine line between supported decision-making and substitute decision-making, or continue to allow for the denial of legal capacity and substitute decision-making under certain circumstances. Even where progressive legislation can be identified, meaningful impact can only be achieved through the participation of persons with disabilities in drafting the law and with the corresponding support to implementing the legislation, such as through appropriate training to legal professionals, including judges.

Extra-legal initiatives are also key to ensure a proper implementation of supported decision-making. These include support in providing information, advance planning, independent advocates, community support networks, and peer support. Such initiatives are often developed by NGOs and DPOs, who have been increasingly active in developing tools or projects to support people with disabilities in their decision-making. The most efficient support systems for persons with disabilities are those that are designed, developed and delivered with the participation of all stakeholders, notably including persons with disabilities.

Only a collaborative effort among persons with disabilities, policy-makers, service providers, families, legal professionals, health professionals and carers, coupled with the allocation of sufficient resources, will allow states to comply with their human rights obligations under Article 12 of the Convention.

The unique mandate of NHRIs gives them a crucial role in making supported decision-making a reality everywhere in Europe.

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ENNHRI and its CRPD Working Group

ENNHRI, the European Network of National Human Rights Institutions, works to enhance the promotion and protection of human rights in Europe through strengthening, supporting and connecting European NHRIs. We are made up of over 40 institutions across Europe. Our network provides a platform for collaboration and solidarity in addressing human rights challenges and a common voice for NHRIs at the European level. Our work on the rights of persons with disabilities is facilitated through our CRPD Working Group, which brings together over 30 European NHRIs to exchange knowledge, good practices and challenges.

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Mental Health Europe

Mental Health Europe (MHE) is a European non-governmental network organisation working for the promotion of positive mental health, the prevention of mental distress, and the improvement of care and community-based recovery. We continuously champion social inclusion and the protection of the rights of (ex)users of mental health services, persons with psychosocial disabilities, their families and carers. We raise awareness to end mental health stigma throughout Europe. The United Nations Convention on the Rights of Persons with Disabilities is the foundation of our work.

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