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Legal capacity of persons with intellectual disabilities and persons with mental health problems

This report address matters related to, in particular, the principle of equality before the law (Article 20), non-discrimination (Article 21) and the integration of persons with disabilities (Article 26) falling under Chapter III 'Equality' of the Charter of Fundamental Rights of the European Union.

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Legal capacity of persons with intellectual disabilities and persons with mental health problems

Foreword

The Convention on the Rights of Persons with Disabilities (CRPD), adopted by the United Nations General Assembly in December 2006, transformed the approach taken by international human rights law to guaranteeing the equal rights of persons with disabilities. It wrested the focus away from long-held stereotypes that the 'problem' rested with a person's impairment, and directed it instead at the 'disabling' barriers society puts up and its responsibility to tear them down and accommodate the needs of persons with disabilities.

Yet the gap yawns wide between what the 21st century's first human rights treaty promises on paper and the lived reality of persons with disabilities, the European Union Agency for Fundamental Rights (FRA) found in its first research project on the subject. Societal barriers, ranging from laws and policies to attitudes and a lack of appropriate support, continue to prevent persons with intellectual disabilities and persons with mental health problems from enjoying their fundamental rights on an equal basis with others.

Equality means, for example, having the power to take independent decisions – a power all too often denied to persons with mental health problems and persons with intellectual disabilities when restrictive legal capacity legislation keeps them from making legally recognised decisions. Article 12 of the CRPD on equal recognition before the law triggers a significant change in approach to the issue of legal capacity, empowering persons with disabilities to have control over their lives.

The FRA uses legal and sociological research methods to highlight discrepancies between the CRPD – ratified by 24 European Union Member States and the EU itself, the first supranational government to ratify a human rights treaty – and the implementation of its standards on the ground. This report analyses the current international and European legal standards and compares EU Member States' laws in the area of legal capacity. Evidence from fieldwork research supports the legal analysis, providing eloquent testimony to the obstacles many persons with disabilities face in securing equal enjoyment of their fundamental rights.

The CRPD is already driving significant reforms in the legal capacity regimes in many EU Member States and is likely to soon bring about similar change in others. This FRA analysis is designed to feed into this process, helping narrow and eventually close the gap between the promise of the law and the reality those with disabilities face in the EU every day.

Morten Kjaerum

Director

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Executive summary

The right to equal recognition of a person before the law is a long-established human rights principle reflected in national and international legal frameworks, which nonetheless coexists with regimes that abridge, under certain conditions, the legal capacity of persons with intellectual disabilities and persons with mental health problems. With the entry into force of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), however, the issue of legal capacity needs to be interpreted in light of the convention's paradigm shift towards a rights-based approach to disability. This approach expressly links equal recognition before the law to the principles of non-discrimination and equality for those with disabilities. The number of EU Member States currently reforming existing legislation in the area of legal capacity testifies to the fundamental reconsideration required by the CRPD's shift in approach.

This report presents the European Union Agency for Fundamental Rights' (FRA) legal analysis of current standards and safeguards concerning the legal capacity of persons with intellectual disabilities and persons with mental health problems. It twins this analysis with the lived experiences of a small number of interviewees regarding the loss of legal capacity and other restrictions on their ability to take decisions. This socio-legal approach provides an overview of the legal situation in an area of rapid and significant reform with an insight into how such laws impact the daily lives of those they most directly affect.

Although the CRPD does not set out a prohibition of restrictions on legal capacity, its Article 12 requires that those states that have ratified the treaty recognise that persons with disabilities have legal capacity on an equal basis with others in all aspects of life, and that disability alone does not justify the deprivation of legal capacity. The treaty's monitoring body, the CRPD Committee, has called, for example, for ratifying states to replace substituted with supported decision-making regimes. At the Council of Europe level, standards relating to legal capacity involve the junction of several interrelated rights, notably the right to private life and the right to a fair trial. Council of Europe standards clearly permit the restriction of legal capacity if certain conditions are fulfilled and safeguards put in place. As with the CRPD, however, the existence of a disability alone does not justify the deprivation of legal capacity, and

any restriction must be both tailored to the individual's circumstances and proportional to his or her needs.

This report shows that the current legal situation across the EU, despite a degree of national variety, is marked by a number of commonalities. To restrict an individual's legal capacity, nearly all EU Member States require that an intellectual disability or mental health problem be coupled with a second criterion linked to the person's 'inability' to manage his or her affairs. Typically, following a decision of legal incapacity, a guardian is appointed. National legislation in all EU Member States allows for an appeal of the decision depriving a person of legal capacity and appointing a guardian, although several Member States do not require the person concerned to actively participate in these proceedings.

Interviews with persons with mental health problems and persons with intellectual disabilities underline the impact that legal capacity legislation can have on the everyday lives of persons with disabilities. While recalling very different situations, participants who lost their legal capacity shared a sense of powerlessness and described experiences often characterised by a lack of explanation or an opportunity to challenge the process. Once appointed a guardian, respondents expressed frustration at the restrictions on their ability to take decisions for themselves, although some welcomed the support that guardians could provide. Nevertheless, very few challenged the decision to deprive them of their legal capacity or to change their guardian, in some cases because their very lack of capacity left them unable to initiate such proceedings.

Informal restrictions on many participants' freedom to take decisions about their lives, whether living in institutions or in the community, compounded legal measures to limit or remove their legal capacity. Often stemming from paternalistic attitudes and low expectations of persons with disabilities, participants' responses showed that these practices served to undermine their ability to make choices about their lives even when they retained their full legal capacity. Participants reflected positively, in contrast, on a range of ways they were supported to take decisions for themselves, underlining how the provision of freely chosen and personalised support can empower persons with disabilities and promote autonomy.

Introduction

“Article 12 of the Convention on the Rights of Persons with Disabilities requires States parties to recognize persons with disabilities as individuals before the law, possessing legal capacity, including capacity to act, on an equal basis with others. [...] The centrality of this article in the structure of the Convention and its instrumental value in the achievement of numerous other rights should be highlighted.”

United Nations, General Assembly Human Rights Council (2009), Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, A/HRC/10/48, 26 January 2009, paragraph 43

“Independence and personal autonomy is not about being able to do everything on your own, but about having control of your life and the possibility to make decisions and have them respected by others.”

Council of Europe, Commissioner for Human Rights, Human rights and disability: Equal rights for all, Comm DH/Issue Paper (2008) 2

With the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006, the United Nations General Assembly profoundly altered how international law views the rights of persons with disabilities. The CRPD incorporates a paradigm shift that considers persons with disabilities as holders of rights on an equal basis with others rather than as recipients of charity. This shift captures the evolution to a ‘social model’ from a ‘medical model’ of disability in which “people are [now] viewed as being disabled by society rather than by their bodies”.¹ Consequently, CRPD-ratifying states need to take measures to ensure the removal of those barriers which prevent persons with disabilities from being fully equal members of society.

The CRPD clarifies the obligations of those states that have ratified it to ensure that persons with disabilities enjoy, in an equal manner, all international human rights. The CRPD does not create new rights; it rather complements existing civil, political, economic and social rights. The CRPD focus on non-discrimination and equal treatment, accessibility and inclusion is driving a reassessment of existing approaches and legislation regarding persons with disabilities. Ratified by 24 EU Member States and by the European Union (EU) itself in December 2010, the CRPD has a crucial bearing on how EU Member States design policies and legislate on issues concerning persons with disabilities. Recent reforms of national legislation have already taken CRPD guarantees into consideration. The European Court of Human Rights (ECtHR) regularly cites the convention in its case law. The convention is thus helping set standards at Council of Europe and EU level.²

Amid this broader reassessment of the rights of persons with mental health problems and persons with intellectual disabilities, legal capacity and substituted or supported decision-making represent central concerns.

Supported decision-making: where a support person enables a person with a disability to take and communicate decisions with respect to personal or legal matters.⁴ With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person explains the issues, when necessary, and interprets the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person should enable that person to exercise their legal capacity to the greatest extent possible, according to the latter’s wishes and/or best interests.⁵

Substituted decision-making: where the legal representative, guardian or tutor has court-authorised power to take decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in the individual’s best interest or according to his or her wishes.

Article 12 of the CRPD recognises that persons with disabilities are “persons before the law” and have legal capacity on an equal basis with others. The convention facilitates a shift away from ‘substituted decision-making’ towards more individually tailored systems of support.⁶

There is no internationally accepted definition of legal capacity. This report takes legal capacity to be the law’s recognition of the decisions that a person takes: it makes a person a subject of law, and a bearer of legal rights and obligations. Without such recognition, an individual’s decisions have no legal effect or validity; they cannot make binding decisions.

Legal capacity is a particularly challenging and complex issue because it affects all areas of life, from choosing where to live and whether and whom to marry, to signing an employment contract, casting a vote or managing property – as specifically highlighted in Article 12 paragraph 5 of the CRPD. The right to legal capacity is, therefore, closely entwined with many CRPD rights, including equality and non-discrimination. In conjunction with the CRPD’s rights-based approach to disability, where the person is at the centre of all decisions affecting him- or herself,⁷ this has profound implications for legal capacity legislation and its implementation.

3 United Nations (UN), General Assembly Human Rights Council (2009), para. 45.

4 *Ibid.*, p. 90.

5 UN (2007), p. 89.

6 Schulze, M. (2010), p. 86.

7 Quinn, G. and Degener, T. (2002), p. 14.

1 World Health Organization (WHO) (2011), p. 4.

2 European Commission (2010).

Legal capacity is also a sensitive issue because traditionally – emulating the ‘medical model’ of disability – legislation reflected the assumption that some people with disabilities could not take decisions for themselves and required protection both from abuse and from the consequences of ‘bad’ decisions. It remains a highly topical issue: reforms are on-going in a number of EU Member States and the interpretation of Article 12 remains a matter of debate.⁸

EU-level discussions display the shifting approaches to legal capacity and the prominence of the issue within debates on the rights of persons with disabilities. In its first report, the EU Disability High Level Group (DHLG) highlighted the importance and complexity of legal capacity, which it identified as an area of law requiring consultation and reflection.⁹ The DHLG acknowledged that although “the European Community does not have competence in this area, it recognises the crucial importance of Article 12 of the UN Convention for the full enjoyment of all human rights by persons with disabilities and their independence”.¹⁰ The European Disability Strategy 2010–2020 underlines this approach and specifically highlights legal capacity as an area where the EU can promote the conformity of Member State legislation with the CRPD.¹¹

These EU policy developments followed a series of initiatives taken in previous years in a wider European context. In 1999¹² and 2009,¹³ the Council of Europe Committee of Ministers adopted recommendations on the legal protection of incapable adults and planning for future incapacity; and in 2009, the Council of Europe Parliamentary Assembly passed a resolution inviting member states to guarantee that persons with disabilities retain and exercise legal capacity on an equal basis with others.¹⁴ Meanwhile, the case law of the European Court of Human Rights (ECtHR) documents specific violations of human rights of persons with disability and, in particular, persons with disabilities who are deprived of their legal capacity.

Terminology

The CRPD does not provide a specific definition of disability.¹⁵

CRPD

Article 1 – Purpose

Persons with disabilities include those who have long-term physical, mental, intellectual and sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Paragraph (e) of the Preamble to the CRPD acknowledges that disability is an evolving concept and that there are therefore no commonly agreed terms to describe the persons with intellectual disabilities and persons with mental health problems covered by this report. The terminology varies between jurisdictions, professions and persons with disabilities themselves as well as across geographic regions. During the period this research was carried out, the terms used by international bodies changed.¹⁶ Despite differences in terminology, all the organisations agreed that disability was a human rights issue and its consequences were the result of an individual’s interaction with society.¹⁷

In the absence of a common terminology, and after consultation with disabled persons’ organisations (DPOs), FRA uses the terms ‘persons with mental health problems’ and ‘persons with intellectual disabilities’ in its reports.¹⁸ Inclusion Europe, an association of persons with intellectual disabilities and their families,¹⁹ and the European Platform of Self-Advocates,²⁰ a network of persons with intellectual disabilities, use the term ‘persons with intellectual disabilities’. The term ‘persons with mental health problems’ was regarded as more accessible to laypersons and non-fluent English speakers, although the World Network of Users and Survivors of Psychiatry,²¹ the International Disability Alliance,²² a world-wide disability non-governmental organisation (NGO), and the UN Committee on the Rights of Persons with Disabilities (CRPD Committee)²³ favour the term ‘psycho-social disability’. This term is not used by the European Network of (ex) Users and Survivors of Psychiatry (ENUSP).²⁴ The reluctance of many people with psychiatric diagnoses to identify themselves as ‘disabled’ has spurred a debate about the relationship

8 For more information, see: Dhanda, A. (2007), pp. 455–456; Bach, M. (2009).

9 European Commission, Disability High Level Group (2008), p. 35.

10 European Commission, Disability High Level Group (2009), p. 217.

11 European Commission (2010), Areas of action 3, p. 7.

12 Council of Europe, Committee of Ministers (1999).

13 Council of Europe, Committee of Ministers (2009a).

14 Council of Europe, Parliamentary Assembly (2009).

15 European Union Agency for Fundamental Rights (FRA) (2011a), p. 9.

16 See FRA (2012a), p. 11.

17 WHO (2011), Council of Europe, Committee of Ministers (2006); European Commission (2010), European Commission (2009).

18 All FRA publications on the fundamental rights of persons with intellectual disabilities and persons with mental health problems are available at: <http://fra.europa.eu/en/theme/people-disabilities>.

19 See: www.inclusion-europe.org/en/about-us.

20 See: www.inclusion-europe.org/en/self-advocacy.

21 See: www.wnusp.net/.

22 See: www.internationaldisabilityalliance.org/en.

23 See, for example: UN, Committee on the Rights of Persons with Disabilities (CRPD Committee) (2012a), para. 6.

24 See: www.enusp.org.

between mental health and disability and contributed to the decision to use the term ‘persons with mental health problems’ in this report.²⁵

Intellectual disability and mental health problems are separate and distinct phenomena. They have generated different political movements, are associated with different types of experiences and responses and often have quite different concerns. In this report, in order to avoid repetition, reference is made to ‘persons with disabilities’ in the spirit of the CRPD. This is not intended in any way to undervalue the important differences between persons with intellectual disabilities and persons with mental health problems. The report also refers to ‘groups of persons’, although it is recognised that individual experiences vary greatly.

Furthermore, there is a wide range of different terms employed to discuss the issues surrounding legal capacity and, in particular, the individual who is legally empowered to take decisions on another’s behalf. The loss of legal capacity is, for example, distinct from the ‘introduction of a protective measure’. In this report, the term ‘introduction of a protective measure’ refers to the placement of an individual under guardianship and not to the loss of the person’s legal capacity. Under ‘guardianship’, a legal representative (a guardian), takes legally binding decisions for the person placed under a protective measure, a process known as ‘substituted decision-making’. While EU Member States use a variety of other terms to describe individuals who are given various powers and responsibilities in the decision-making process, in this report the terms ‘guardianship’ and ‘guardian’ will be used to describe all situations in which a third party is legally entitled to take decisions on behalf of another person. In another process, known as ‘supported decision-making’, an individual is assisted in the decision-making process but retains the full power to make decisions recognised under law.

Plenary guardianship: “Those under full or plenary guardianship, [...] lose all or almost all of their civil rights. The involvement of the guardian is then necessary to make legally effective decisions in most areas of life.”²⁶

Partial guardianship: “Persons under partial guardianship keep the main bulk of their civil rights but certain capacities are transferred to a legal representative, most commonly the power to manage financial affairs.”²⁷

In its presentation of the lived experiences of persons with disabilities with regard to legal capacity, this report

distinguishes between ‘formal’ and ‘informal’ restrictions on decision-making. ‘Formal’ restrictions of legal capacity are those in which an individual loses his or her power to take decisions recognised by law, wholly or in part, as a result of legal measures. This usually involves a court decision to deprive someone of his or her legal capacity, followed by the appointment of a guardian who takes legally binding decisions on his or her behalf (see Chapters 2 and 3). ‘Informal’ restrictions of legal capacity are often independent of any formal legal measure. They include factors and practices which restrict the ability of a person to take decisions about his or her life, such as institutional regimes or paternalistic attitudes based on the assumption that persons with disabilities cannot take decisions for themselves as they do not understand the likely consequences of their actions, and it is therefore in their best interest if decisions are taken on their behalf (see Chapter 3).

Project background and scope of the report

FRA focused its attention on the fundamental rights of persons with disabilities by collecting evidence on the situation of two groups that have, to date, received little research attention, namely persons with intellectual disabilities and persons with mental health problems.

FRA carried out comparative legal research and analysis across the EU, examining the current legal frameworks. In addition, it launched qualitative fieldwork research in nine EU Member States that reflect a mix of disability policies (Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden and the United Kingdom). The fieldwork research engaged directly with persons with intellectual disabilities and persons with mental health problems as well as with the people who have a direct impact on their lives: their families and carers, service providers, and health, disability and legal professionals. The fieldwork research enhances understanding of how persons with mental health problems and persons with intellectual disabilities experience the fulfilment of their rights.

The report *The right to political participation of persons with mental health problems and persons with intellectual disabilities*, published in 2010, contains the first part of the legal analysis, and was followed in 2011 by a second report on *The legal protection of persons with mental health problems under non-discrimination law*.

In June 2012, FRA organised an international conference at which participants discussed issues relating to legal capacity and FRA research findings in the area of disability.²⁸ The conference, entitled ‘Autonomy and inclusion

²⁵ See, for example: Beresford, P. (2000), pp. 167–172.

²⁶ Council of Europe, Commissioner for Human Rights (2012a), section 2.1.

²⁷ *Ibid.*

²⁸ See: <http://fra.europa.eu/en/event/2012/despite-legislation-disability-rights-not-realised-practice>.

of persons with mental health problems and persons with intellectual disabilities', was held in partnership with the Danish Ministry of Social Affairs and Integration under the auspices of the Danish Presidency of the Council of the European Union and with the cooperation of the Danish Institute of Human Rights and Danish disabled persons' organisations.

The conference also marked the launch of two additional FRA reports. FRA published its key findings from its legal and fieldwork research on involuntary placement and involuntary treatment in *Involuntary placement and involuntary treatment of persons with mental health problems*. The second report, *Choice and control: the right to independent living*, presents the findings of FRA's interview-based fieldwork research with persons with mental health problems and persons with intellectual disabilities, and examines how they experience the principles of autonomy, inclusion and participation in their day-to-day lives.

The present report brings together the key findings of the legal analysis and the fieldwork research on the issue of legal capacity. The legal analysis is based on information provided by FRA's network of legal experts, FRALEX.²⁹ Evidence presenting the actual experiences of persons with mental health problems and persons with intellectual disabilities concerning legal capacity is based on individual, semi-structured interviews with 115 persons with mental health problems and 105 persons with intellectual disabilities, in addition to focus group interviews with relevant stakeholders in the nine EU Member States where FRA conducted fieldwork. This primary research complements and deepens the legal analysis by showing how individuals experience the consequences of these legal processes in practice.

Legal capacity assumes many forms in EU Member States' legislation. This report focuses on civil law measures and therefore excludes specific rules that apply in a criminal or juvenile context. The legal analysis does not assess the practical implementation of the relevant legislation, nor the extent to which the CRPD requires reforms at EU Member State level. Instead, it describes the way national and international law address the issue of legal capacity and provides fundamental rights guarantees to persons with disabilities. The report offers EU institutions and EU Member States comparable information on the current situation in the 27 EU Member States.

Thematic reports on the situation of persons with mental health problems and persons with intellectual disabilities in each Member State provided further contextual information.³⁰ Additional information was gathered through exchanges with key partners, including the Danish Institute for Human Rights and individual experts including Professor Gerard Quinn, Galway University, Ireland; Oliver Lewis, Executive Director, Mental Disability Advocacy Center; and Marianne Schulze. FRA expresses its gratitude for these valuable contributions. The opinions and conclusions in this report do not necessarily represent the views of the organisations or the individual experts who helped to develop the report.

The report is divided into three chapters. It first presents an overview of international and European standards and safeguards for the protection of persons with disabilities, providing the international legal context of legal capacity. The second chapter describes EU Member States' national legislation, providing an overview of the approaches to, and frameworks governing, legal capacity at the national level. The third chapter presents evidence of the lived experience of persons with mental health problems and persons with intellectual disabilities related to legal incapacity and guardianship, informal restrictions on decision-making and supported decision-making. The last chapter also presents a snapshot of individuals' experiences of making choices and taking decisions about their own lives.

29 All national studies are available for download at: <http://fra.europa.eu/en/country-report/2012/country-thematic-reports-fundamental-rights-persons-intellectual-disabilities>.

30 For additional information regarding the social research methodology, see FRA (2012b).



1

International and European standards



A discussion on the legal capacity of persons with disabilities is linked to many of the fundamental rights guaranteed under the Charter of Fundamental Rights of the European Union. Most prominently, it concerns the basic principles of equality and non-discrimination set out in: Article 21 on non-discrimination; Article 20 on equality before the law; and Article 26 on the integration of persons with disabilities. But since legal capacity impacts many areas of life, a number of other fundamental rights could also be mentioned. Unlike the CRPD, however, the Charter applies only to Union Law and when EU Member States implement Union Law (Article 51 (1) of the Charter).

With the ratification of the CRPD by the EU, the treaty became part of the EU legal order, creating legal obligations that fall in the area of EU competence. While the Charter of Fundamental Rights of the European Union sets out the principle of equality before the law (Article 20), the EU does not have competence to deal with specific questions related to the legal capacity of persons with disabilities. Restrictions on the legal capacity of persons with disabilities can, however, also raise issues of discrimination and equality. Article 21 on non-discrimination could thereby affect how legal incapacity measures are implemented at national level, in regard to employment and training.³¹ The implementation could also affect rights in other life spheres, if secondary EU legislation, as proposed in the Horizontal Directive, were extended to protect individuals from discrimination on the grounds of disability as extensively as it protects them from discrimination on the grounds of racial or ethnic origin.

Several key EU documents, as well as the work of EU bodies and institutions, reflect the coordinating role that EU institutions can play in the area of legal capacity. The European Disability Strategy 2010–2020 notes that: “EU action will support and supplement national policies and programmes to promote equality, for instance by promoting the conformity of Member State legislation on legal capacity with the [CRPD]”.³² In addition, the European Commission funded a report on challenges to CRPD implementation, which highlighted a number of issues, including a lack of distinction between ‘assistants to support persons with disabilities in decision-making’ and ‘guardians’, that triggered the interpretative declarations that some states have submitted, or may consider submitting, in relation to Article 12 of the CRPD on the full recognition of persons with disabilities before the law.³³ FRA affirmed the centrality of the right to legal capacity to enjoy other rights and entitlements in its 2010 report on the participation of persons with disabilities in political life³⁴ and its 2012 report on the right to independent living.³⁵ The FRA report also notes the importance of legal standing for access to justice.³⁶

The EU Disability High Level Group (DHLG) provided further insight into the EU approach to legal capacity, calling it, in its first annual report in 2008, a “common challenge” to be addressed and highlighting the importance of exchanging experiences of measures to implement the convention.³⁷ Recognising that legal capacity is a “complex area of law and requires consultation and reflection”, the DHLG notes that the CRPD would imply changing an approach in which legal capacity

³¹ Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation, OJ 2000 L 303.

³² European Commission (2010), Areas of action 3, p. 7.

³³ European Foundation Centre (2010).

³⁴ FRA (2010).

³⁵ FRA (2012b).

³⁶ FRA (2011b), Section 3.1.2.

³⁷ European Commission, Disability High Level Group (2008).

is “related to mental illness, mental disability or other mental disorder that makes a person permanently unable to understand or direct his/her actions and therefore a guardian is appointed by a court”. The CRPD “will provide for access for persons with disabilities to the support they may require in exercising their legal capacity”, it added.³⁸

1.1. United Nations standards

The 2006 adoption of the CRPD inaugurated a new era of human rights guarantees for persons with disabilities. The convention marks a paradigm shift away from a view of disability centred on medical impairments to one where the full and equal rights of persons with disabilities are embraced. Based on the principles of non-discrimination, equal opportunity and human rights, it enshrines in international law a rights-based approach to disability.³⁹ To understand the significance of this new mindset for the topic of legal capacity, this report first examines how other bodies within the UN legal system have addressed the issue of equality before the law, both directly and indirectly in broader non-discrimination terms. Older instruments will need to be interpreted in light of the CRPD.⁴⁰

International Covenant on Civil and Political Rights

Article 16

Everyone shall have the right to recognition everywhere as a person before the law.

The right to equal recognition before the law is a long-established human rights principle enshrined in a number of key UN treaties. Article 6 of the Universal Declaration of Human Rights and Article 16 of the International Covenant on Civil and Political Rights (ICCPR) both guarantee this right.⁴¹

Although Article 16 of the ICCPR has generated little case law,⁴² the Human Rights Committee recognised its relevance in conjunction with other rights such as non-discrimination (Articles 2, 3 and 26 of the ICCPR), arguing “that the term ‘discrimination’ as used in the Covenant should be understood to imply any distinction,

exclusion, restriction or preference which is based on any ground [...] and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms”.⁴³ More recently, the Human Rights Committee expressed its concern regarding legal representation of legally incapacitated persons.⁴⁴ Other UN treaty bodies have adopted similar approaches. The Committee on Economic, Social and Cultural Rights said, for example, that discrimination “could include the denial of a person’s legal capacity because he or she is in prison, or is involuntarily interned in a psychiatric institution.”⁴⁵

Since the entry into force of the CRPD, other UN bodies have highlighted the link between legal capacity and the fulfilment of other fundamental rights. The Office of the UN High Commissioner for Human Rights (OHCHR) expresses the view that measures to protect and fulfil the right to legal capacity are necessary to provide “legal recognition of the right of persons with disabilities to self-determination.”⁴⁶ Moreover, the UN Special Rapporteur on Torture first linked deprivation of legal capacity to torture and ill-treatment of people with disabilities in 2008.⁴⁷ In 2013, the Special Rapporteur confirmed this approach, saying: “fully respecting each person’s legal capacity is a first step in the prevention of torture and ill-treatment”.⁴⁸ The 2013 report focuses on abuses in healthcare settings, in particular in cases of involuntary placement and involuntary treatment. The Special Rapporteur forcefully reiterates the position adopted by his predecessor in 2008, calling for clear criteria established by law that would specify when a “treatment can be administered in the absence of free and informed consent”.⁴⁹ In providing for these safeguards, the law should make “no distinction between persons with or without disabilities”.⁵⁰ Only life-threatening emergencies could justify life-saving medical interventions without informed consent. In these cases, “there is no disagreement regarding absence of legal capacity”.⁵¹

The central and cross-cutting nature of Article 12 of the CRPD and its clear focus on supported decision-making appears to be challenging, with a number of State Parties making formal declarations on the issue upon ratification:

³⁸ *Ibid.*, p. 35.

³⁹ For more information regarding the evolution in international standards on the rights of persons with disabilities, see: FRA (2011a).

⁴⁰ UN, Office of the High Commissioner for Human Rights (OHCHR), Regional Office for Europe (2011), p. 8.

⁴¹ For a more detailed discussion of the history of recognition before the law and legal capacity in UN treaties, see: UN, OHCHR (2005).

⁴² Joseph, S., Schultz, J. and Castan, M. (2004), p. 299 f; and Nowak, M. (2005), p. 372.

⁴³ UN, OHCHR (1989), para. 7. See also: UN, Human Rights Committee (2000), para. 19.

⁴⁴ UN, Human Rights Committee (2012), para. 14.

⁴⁵ UN, Committee on Economic, Social and Cultural Rights (2009), para. 27.

⁴⁶ UN, Human Rights Council (2009), para. 45.

⁴⁷ UN, Special Rapporteur on Torture (2008), para. 50.

⁴⁸ UN, Special Rapporteur on Torture (2013), p. 15.

⁴⁹ *Ibid.*, para. 66.

⁵⁰ *Ibid.*

⁵¹ UN, Special Rapporteur on Torture (2013), para. 66.

“The Republic of Estonia interprets Article 12 of the Convention as it does not forbid to restrict a person’s active legal capacity, when such need arises from the person’s ability to understand and direct his or her actions. In restricting the rights of the persons with restricted active legal capacity the Republic of Estonia acts according to its domestic laws.”⁵²

“The Republic of Poland declares that it will interpret Article 12 of the Convention in a way allowing the application of incapacitation, in the circumstances and in the manner set forth in the domestic law, as a measure indicated in Article 12(4), when a person suffering from a mental illness, mental disability or other mental disorder is unable to control his or her conduct.”⁵³

Article 12 of the CRPD reaffirms and expands the principle of equal recognition before the law, providing the fullest elaboration of legal capacity in the context of disability. As the most wide-reaching and important international standard, each element of the article will be presented in turn, along with the CRPD Committee’s initial interpretation and the Committee’s reporting guidelines,⁵⁴ and, where relevant, that of other UN human rights bodies.

CRPD

Article 12 – Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

Article 12 (1) of the CRPD restates the basic principle of recognition before the law. This passive recognition establishes identity before the law, but it does not encompass the ability to act that is required for exercising legal capacity. In its Concluding Observations on Peru, the CRPD Committee highlights the importance of recognition, expressing its concern that “a number of persons with disabilities, especially those living in rural areas and in long-term institutional settings, do not have identity cards and, sometimes, have no name”⁵⁵ and urging the State Party to “promptly initiate programmes in order to provide identity documents to persons with disabilities, including in rural areas and in long-term institutional settings”.⁵⁶

CRPD

Article 12 – Equal recognition before the law

2. States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Article 12 (2) of the CRPD complements Article 12 (1) by conferring the ability to act on those whom Article 12 (1) identifies as rights holders. It also highlights the intrinsic non-discrimination aspect of equal recognition before the law – and the place of non-discrimination and autonomy, including the freedom to make one’s own choices, as general principles of the convention – by stipulating that states must recognise that “persons with disabilities enjoy legal capacity on an equal basis with others”. The reporting guidelines provide some further indication of signatories’ equality obligations by asking States Parties to report on “whether legislation does or does not exist which restricts the full legal capacity on the basis of disability”. The OHCHR is more explicit in its interpretation of non-discrimination on the grounds of disability in Article 12. Noting that “legislation currently in force in numerous countries allows the interdiction or declaration of incapacity of persons on the basis of their mental, intellectual or sensory impairment and the attribution to a guardian of the legal capacity to act on their behalf”, it argues:

“Whether the existence of a disability is a direct or indirect ground for a declaration of legal incapacity, legislation of this kind conflicts with the recognition of legal capacity of persons with disabilities enshrined in article 12, paragraph 2.”⁵⁷

Article 12 (2) also plays an important role in extending legal capacity to “all aspects of life.” This suggests the cross-cutting nature of Article 12 and its “instrumental value in the achievement of numerous other rights”⁵⁸ including: Article 4 (3) on deciding whether and how to participate in the development and implementation of legislation and policies affecting people with disabilities; Article 13 on accessing courts and non-judicial mechanisms; Article 14 on the right to liberty and security; Article 19 on decisions about where and with whom to live; Article 23 on deciding about family and relationships; Article 24 on deciding on educational options; Article 25 on healthcare decisions; Article 27 on employment decisions; Article 29 on deciding whom to vote for and deciding which organisations and political parties to join;⁵⁹ and Article 33 on deciding to participate in monitoring CRPD implementation.

⁵² UN, CRPD, Declarations, Estonia.

⁵³ UN, CRPD, Interpretative Declaration made upon ratification, Poland. See also similar declaration from Australia and Canada.

⁵⁴ UN, CRPD Committee (2009).

⁵⁵ UN, CRPD Committee (2012a), para. 23.

⁵⁶ *Ibid.*

⁵⁷ UN, General Assembly Human Rights Council (2009), para. 45.

⁵⁸ *Ibid.*, para. 43.

⁵⁹ FRA (2010).

The CRPD Committee establishes Article 12 as central in the convention by referring to legal capacity in its interpretation of other articles. In its Concluding Observations on Spain, for example, the committee expresses concern that “persons with disabilities whose legal capacity is not recognised may be subjected to sterilisation without their free and informed consent” (Article 17) and that “the right to vote of persons with intellectual or psycho-social disabilities can be restricted if the person concerned has been deprived of his or her legal capacity”⁶⁰ (Article 29). Conversely, in the Concluding Observations on Argentina, the committee confirmed the pertinence of the right to legal capacity, expressing concern that “the right to form a family is denied to some persons with disabilities, especially those declared ‘insane’ or ‘lacking legal capacity’” (Article 23) and that “restrictions on the exercise of legal capacity that exclude persons with disabilities from taking decisions concerning their own [health] treatment” (Article 25).⁶¹

More broadly, it reiterates this issue in its Concluding Observations on Hungary, recommending that Hungary “use effectively the current review process of its Civil Code and related laws to take immediate steps to derogate guardianship in order to move from substitute decision-making to supported decision-making, which respects the person’s autonomy, will and preferences and is in full conformity with Article 12 of the Convention, including with respect to the individual’s right, on their own, to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry, to work, and to choose their place of residence.”⁶²

CRPD

Article 12 – Equal recognition before the law

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Article 12 (3) marks a further expansion on previous concepts of the right to equal recognition before the law by explicitly obliging states to provide access to the support persons with disabilities may require to exercise their legal capacity. It emphasises that the need for such support is not automatic, but that it ‘may’ be required to facilitate the exercise of legal capacity. The Committee, for example, recommended to China to set up a system of supported decision-making and include “accommodations and accession to support where necessary

to exercise legal capacity”.⁶³ This reflects the general principles of “individual autonomy including the freedom to make one’s own choices, and independence of persons” set out in Article 3 of the CRPD.

The CRPD Committee has emphasised the critical importance of providing persons with disabilities with the access to the support they may require to take decisions. In all of its Concluding Observations to date, it has also urged states to replace substituted decision making with supported decision making. The CRPD Committee also recommends that State Parties “provide training, in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels for all actors, including civil servants, judges, and social workers, on the recognition of the legal capacity of persons with disabilities and on mechanisms of supported decision-making.”⁶⁴

In addition, the CRPD Committee underlines the importance of training for persons providing support for decision-making.⁶⁵ Reflecting the CRPD’s general obligation on States Parties “to promote the training of professionals and staff working with persons with disabilities in the rights recognised in the present convention so as to better provide the assistance and services guaranteed by those rights”, it recommends that “training be provided on this issue to all relevant public officials and other stakeholders”.⁶⁶

CRPD

Article 12 – Equal recognition before the law

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

The obligations set out in Article 12 (3) must be read in conjunction with Article 12 (4), which requires

⁶⁰ UN, CRPD Committee (2011a), paras. 37 and 47.

⁶¹ UN, CRPD Committee (2012b), paras. 35 and 39.

⁶² UN, CRPD Committee (2012c), para. 26.

⁶³ UN, CRPD Committee (2012d), para. 22.

⁶⁴ UN, CRPD Committee (2012c), para. 26.

⁶⁵ The need for training of professionals and staff working with persons with disabilities is set out in the General Obligations of the CRPD in Art. 4 (1) (i).

⁶⁶ UN, CRPD Committee (2011b), para. 23; and (2011a), para. 33.



States Parties to establish “appropriate and effective safeguards to prevent abuse” in measures related to the exercise of legal capacity. This provision is also closely related to Article 16 of the CRPD on freedom from exploitation, violence and abuse.

The paragraph expands on what is required to make such safeguards “appropriate and effective”. It explains that all measures relating to the exercise of legal capacity must “respect the rights, will and preferences of the person”, be “free from conflict of interest and undue influence”. They must also be individually tailored, time-limited and subject to regular review. The greater the extent to which a measure affects a person’s rights and interests, the stricter the safeguards required.

The CRPD Committee has thus far made relatively little comment on what form these safeguards should take, limiting its statements to acknowledge its concern about “the lack of legal remedies and safeguards, such as independent review and right to appeal, that are in place in order to revoke [guardianship] decisions” in Peru.⁶⁷ In addition, the Committee asks states to report on “safeguards against abuse of supported decision-making models”.⁶⁸

A number of other UN bodies have commented on the importance of safeguards. The OHCHR stresses the importance of measures that facilitate “alternative and augmentative communication”, thereby enabling persons with disabilities to convey their will and preferences, as well as the “establishment of regulations clarifying the legal responsibilities of supporters and their liability”.⁶⁹

Article 12 (4) of the CRPD remains the subject of intense debate and scrutiny over whether it refers to substituted or supported decision-making, and consequently whether it ever permits substituted decision-making or requires the wholesale adoption of supported decision-making methods. Several States Parties have made clear that they interpret the wording as allowing for substituted decision-making in the appropriate circumstances and when subject to safeguards, as illustrated in the declarations previously quoted in this section.

In its Concluding Observations on Hungary and Spain as well as on Argentina, China, Peru and Tunisia, the CRPD Committee, however, recommended the “replacement”⁷⁰ of substituted decision-making with

supported decision-making and the “immediate review of all current legislation that is based on a substitute decision-making model that deprives persons with disabilities of their legal capacity”.⁷¹ The reporting guidelines further ask that States Parties provide information on “the existence of safeguards against abuse of supported decision-making models”, with no mention of substituted decision-making measures.⁷² Similarly, UN guidance for parliamentarians implementing the CRPD refers to Article 12 (4), calling “for safeguards to be put in place to protect against abuse of [...] support mechanisms”.⁷³

These statements forcefully underline the guarantees in Article 12. They support calls to abolish or at least substantially alter national legislation on legal capacity that allows for and organises substituted decision-making models for persons with disabilities, and to replace them with supported decision-making measures that respect the person’s autonomy, will and preferences.

CRPD

Article 12 – Equal recognition before the law

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Article 12 (5) focuses on the rights of persons with disabilities to manage their financial affairs and access financial products and to own and inherit property, and demands that States Parties take measures to ensure the fulfilment of these rights on an equal basis with others. These stipulations relate closely to Article 19 on living independently and being included in the community and Article 27 on work and employment. The CRPD Committee has yet to comment specifically on these aspects of Article 12 in its Concluding Observations, although the reporting guidelines request that states provide information on the measures they have taken to meet the obligations set out in Article 12 (5).⁷⁴

Because the CRPD Committee has not yet commented on all elements of Article 12, no authoritative interpretation of the article exists. To establish with certainty the scope of Article 12 guarantees, it will be crucial to see how the CRPD Committee handles individual

⁶⁷ UN, CRPD Committee (2012a), para. 24.

⁶⁸ UN, CRPD Committee (2009), p. 9.

⁶⁹ UN, General Assembly Human Rights Council (2009), para. 45.

⁷⁰ UN, CRPD Committee on the Rights of Persons with Disabilities (2011b), para. 23; UN, CRPD Committee (2012a), para. 25; UN, CRPD Committee (2011a), para. 34; UN, CRPD Committee (2012d), para. 22.

⁷¹ UN, CRPD Committee (2012b), para. 20.

⁷² UN, CRPD Committee (2009), p. 9.

⁷³ UN, OHCHR (2007), p. 90.

⁷⁴ UN, CRPD Committee (2009), p. 9.

communications, based on the CRPD Optional Protocol, as well as how national monitoring frameworks under Article 33 of the CRPD deal with issues of legal capacity.⁷⁵ A CRPD Committee General Comment on Article 12 would offer considerable insight into the steps States Parties need to take to translate the article's provisions into national law.

In the absence of such an authoritative interpretation, States Parties are asked – based on the Concluding Observations on Argentina, China, Hungary, Peru, Spain and Tunisia – to thoroughly review national legislation that allows for guardianship and to replace regimes of substituted decision making with supported decision making. While this represents a challenge, legal evolution at national level is under way (see Chapter 2).

1.2. Council of Europe standards

Conforming to CRPD obligations will also have a major impact on regional standards. This section further elaborates on current standards the Council of Europe has developed.

The Council of Europe Action Plan 2006–2015 affirms that “People with disabilities have the right to recognition everywhere as persons before the law” and requires member states to ensure that “[...] when assistance is needed to exercise that legal capacity [...] that this is appropriately safeguarded by the law”.⁷⁶ While not dealing particularly with legal capacity, this comprehensive action plan is worth mentioning because it was adopted shortly before the CRPD was open to signature. It aims to put in place a “European policy framework on disability” that is based on “human rights, non-discrimination, equal opportunity, full citizenship and participation of people with disability”.⁷⁷ The Council of Europe Committee of Ministers has adopted recommendations focused on legal capacity, setting out clear principles on the legal protection of incapable adults⁷⁸ and planning for future incapability.⁷⁹ Other relevant standards can be found in Council of Europe recommendations on human rights of persons with mental health problems or in the Convention on Human Rights and Biomedicine (Oviedo Convention).⁸⁰ The Council of Europe Parliamentary Assembly also recommended in its resolution and recommendation, both entitled *Access to*

rights for people with disabilities and their full and active participation in society, that states should “guarantee that people with disabilities retain and exercise legal capacity on an equal basis with other members of society”.⁸¹ Finally, the Council of Europe Commissioner for Human Rights has issued papers and viewpoints on the issue.⁸² These Council of European standards are often supporting the ECtHR judgments.

The European Convention on Human Rights (ECHR) does not contain a specific provision on recognition before the law. The ECtHR has nevertheless produced an extensive body of case law addressing the issue, in particular on the legal capacity of persons with mental health problems and persons with intellectual disabilities. Applicants have brought complaints under: Article 5 on the deprivation of liberty;⁸³ Article 6 on the right to a fair trial;⁸⁴ Article 8 on the right to respect for private and family life;⁸⁵ Article 12 on the right to marry;⁸⁶ as well as under Article 3 of the first Protocol to the convention on the right to participate in free elections.⁸⁷ A number of judgments made specific reference to the CRPD,⁸⁸ reflecting the ECtHR's acknowledgment of “the growing importance which international instruments for the protection of people with mental disorders are now attaching to granting them as much legal autonomy as possible”.⁸⁹

81 Council of Europe, Parliamentary Assembly (2009), para. 7.

82 See, for example: Council of Europe, Commissioner for Human Rights (2012a) and Council of Europe, Commissioner for Human Rights (2012b).

83 See, for example: ECtHR, *Winterwerp v. the Netherlands*, No. 6301/73, 24 October 1979; ECtHR, *Van der Leer v. the Netherlands*, No. 11509/85, 21 February 1990; ECtHR, *H.L. v. the United Kingdom*, No. 45508/99, 5 October 2004; ECtHR, *Shtukatur v. Russia*, No. 44009/05, 27 March 2008; ECtHR, *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012; ECtHR, *D.D. v. Lithuania*, No. 13469/06, 14 February 2012; and ECtHR, *Sýkora v. the Czech Republic*, No. 23419/07, 22 November 2012. See also FRA (2012a), pp. 16 f.

84 For example, ECtHR, *Winterwerp v. the Netherlands*, No. 6301/73, 24 October 1979; ECtHR, *H.F. v. Slovakia*, No. 54797/00, 8 November 2005; ECtHR, *X and Y v. Croatia*, No. 5193/09, 3 November 2011; ECtHR, *Shtukatur v. Russia*, No. 44009/05, 27 March 2008 and ECtHR, *D.D. v. Lithuania*, No. 13469/06, 14 February 2012.

85 See, for example: ECtHR, *Matter v. Slovakia*, No. 31534/96, 5 July 1999; ECtHR, *Berkova v. Slovakia*, No. 67149/01, 24 March 2009; ECtHR, *Shtukatur v. Russia*, No. 44009/05, 27 March 2008; ECtHR, *Sýkora v. the Czech Republic*, No. 23419/07, 22 November 2012; and ECtHR, *Lashin v. Russia*, No. 33117/02, 22 January 2013.

86 See: ECtHR, *Lashin v. Russia*, No. 33117/02, 22 January 2013. In this case, the ECtHR considered that the Article 12 complaint was covered by the Article 8 violation and decided not to examine it (para. 124).

87 For instance, ECtHR, *Alajos Kiss v. Hungary*, No. 38832/06, 20 May 2010. For more on the right to vote in the context of legal capacity see FRA (2010).

88 See, for example: ECtHR, *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012, para. 244; ECtHR, *D.D. v. Lithuania*, No. 13469/06, 14 February 2012, para. 84; ECtHR, *Sýkora v. the Czech Republic*, No. 23419/07, 22 November 2012, para. 41; and ECtHR, *Lashin v. Russia*, No. 33117/02, 22 January 2013.

89 ECtHR, *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012, para. 244.

75 See, for example: Austria, Independent Monitoring Committee (2012); Denmark, Danish Institute for Human Rights (2012).

76 Council of Europe, Committee of the Ministers (2006), Action line No. 12: legal protection, para. 3.12.

77 *Ibid.*, para. 1.1.2.

78 Council of Europe, Committee of Ministers (1999).

79 Council of Europe, Committee of Ministers (2009b).

80 Council of Europe, Committee of Ministers (2004); Council of Europe, Committee of Ministers (2009a). See also Council of Europe (1997).

1.2.1. Restriction of legal capacity and right to liberty

ECHR

Article 5 – Right to liberty and security

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law: [...]
 - (e) the lawful detention of persons [...] of unsound mind [...];
4. Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful [...]

ECtHR case law sheds light on whether and under which circumstances persons with disabilities may have their legal capacity restricted or removed, which can limit their ability to take decisions across many spheres of life, including medical treatment. Key judgments will help illustrate the court's approach and its evolution as human rights law has developed.

Article 5 (1) (e) of the ECHR allows deprivation of liberty of persons with "unsound mind". One potential consequence of the removal of legal capacity is that persons with disabilities may be subject to involuntary placement or involuntary treatment. The FRA report *Involuntary placement and involuntary treatment of persons with mental health problems*⁹⁰ provides a detailed analysis of the circumstances in which persons with disabilities may be placed or treated against their will, but it does not address the issue of compulsory measures in the context of legal incapacity. ECtHR case law documents the relationship between the removal of legal capacity and appointment of a guardian, and the decision to place and/or treat a person involuntarily and its consequences.

The removal of legal capacity often takes place before or concurrently with a placement decision. The individual is not consulted and the decision is taken upon the request of the guardian. If the guardian consents to a placement decision then, legally speaking, it is a voluntary admission, and therefore does not have the same legal safeguards as an involuntary one. Recent ECtHR cases such as *Kędzior v. Poland*,⁹¹ *Sýkora v. the Czech Republic*⁹² or *Mihailovs v. Latvia*⁹³ illustrate this situation. In these cases, the applicants were divested of their legal capacity because of mental health problems

and were placed in social care or psychiatric institutions. The incapacitation curbed the individual's freedom of movement. In the *Kędzior* case, only the guardian could apply for leave of absence from the institution, while in the *Mihailovs* case, when the husband asked for permission to leave the institution, the guardian, his wife, needed to agree. Furthermore, and more importantly for assessing a deprivation of liberty under Article 5 of the ECHR, the legal basis for the deprivation of liberty rests with the guardian's consent to, or request for, placement. In the *Mihailovs* case, the consent of the guardian, the applicant's wife, who was also the person who asked for the placement, was the only condition for Mr Mihailovs' placement. When faced with these facts, the ECtHR acknowledged the lawfulness of the detention under national law, but it concluded that the national legal framework did not provide enough safeguards and was therefore in breach of Article 5 (1) of the ECHR.⁹⁴

The lack of legal capacity also has wide-reaching consequences for applicants wishing to have the lawfulness of their detention under Article 5 (4) of the ECHR reviewed. In the *Kędzior* case, for example, the ECtHR noted that the law does not prescribe periodic reviews of the need for detention when the placement is considered voluntary, and the lack of legal capacity prevented the individual from initiating any judicial remedy against his detention. For the ECtHR, this situation reveals a "lack of an effective regulatory framework" in violation of Article 5 (4).⁹⁵

1.2.2. Decision on incapacity and the right to fair trial

ECHR

Article 6 – Right to a fair trial

1. In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law. Judgment shall be pronounced publicly but the press and public may be excluded from all or part of the trial in the interests of morals, public order or national security in a democratic society, where the interests of juveniles or the protection of the private life of the parties so require, or to the extent strictly necessary in the opinion of the court in special circumstances where publicity would prejudice the interests of justice. [...]

⁹⁰ FRA (2012a).

⁹¹ ECtHR, *Kędzior v. Poland*, No. 45026/07, 16 October 2012.

⁹² ECtHR, *Sýkora v. the Czech Republic*, No. 23419/07, 22 November 2012.

⁹³ ECtHR, *Mihailovs v. Latvia*, No. 35939/10, 22 January 2013.

⁹⁴ See: ECtHR, *Sýkora v. the Czech Republic*, No. 23419/07, 22 November 2012, para. 70; ECtHR, *Kędzior v. Poland*, No. 45026/07, 16 October 2012, para. 70; or ECtHR, *Mihailovs v. Latvia*, No. 35939/10, 22 January 2013, para. 151.

⁹⁵ ECtHR, *Kędzior v. Poland*, No. 45026/07, 16 October 2012, para. 77 and 79. See also: ECtHR, *Sýkora v. the Czech Republic*, No. 23419/07, 22 November 2012, para. 84.

Many ECtHR cases regarding the legal capacity of persons with mental health problems and persons with intellectual disabilities have rested on the right to a fair trial, as set out in Article 6 of the ECHR. The court has consistently reiterated the importance of upholding Article 6, building on the judgment in the case of *Winterwerp v. the Netherlands*, where it stated that “[w]hatever the justification for depriving a person of unsound mind of the capacity to administer his property, the guarantees laid down in Article 6 (1) must nevertheless be respected”.⁹⁶ More recently, while the court reiterated in the case of *X and Y v. Croatia* that “in cases involving a mentally ill person the domestic courts should enjoy a certain margin of appreciation”, it makes clear that “such measures should not affect the very essence of the applicant’s right to a fair hearing as guaranteed by Article 6 of the Convention”.⁹⁷

The ECtHR’s approach to the right to a fair trial in situations of legal incapacity has focused on four elements, namely the right of the person to be heard, the role of the judge, procedural safeguards and the right to access justice. The ECtHR has underlined through a significant body of case law that the person concerned has the right to be heard in person – or, where necessary, through some form of representation – in administrative proceedings leading up to the decision determining his or her legal capacity, as well as during the hearing itself.⁹⁸ In *Shtukurov v. Russia*, for example, the ECtHR ruled that the decision of the judge to withdraw the applicant’s legal capacity on the basis of documentary evidence, without seeing, or hearing from, him or her, was “unreasonable and in breach of the principle of adversarial proceedings” set out in Article 6 (1).⁹⁹ Similarly, the court’s reasoning in *Salontaji-Drobnjak v. Serbia* reflected that “the applicant had been excluded from the final hearing and had therefore been unable to personally challenge the experts’ report recommending the partial deprivation of his legal capacity”.¹⁰⁰

The ECtHR has also emphasised that being under guardianship is not a reason in and of itself for the opinion of the person concerned not to be heard:

“[...] the fact that an individual has to be placed under guardianship because he lacks the ability to administer his affairs does not mean that he is incapable of expressing a view on his situation and thus of coming into conflict with the guardian. In such cases, when the conflict potential has a major impact on the person’s legal situation [...], it is essential that the person concerned should have access to court and the opportunity to be heard either in person or, where necessary, through some form of representation.”¹⁰¹

Case law has also further addressed situations in which third parties have represented persons in the process of losing their legal capacity in court. In the *D.D. v. Lithuania* case, the applicant had been deprived of her legal capacity and appointed a guardian. The guardian’s lawyer then represented the applicant in court proceedings. In ruling that there had been a violation of Article 6 (1), the court found that “because of the conflicting interests of her and her legal guardian, her guardian’s lawyer could in no way have represented her interests properly”. This contravened “the interests of a fair hearing” which “required that the applicant be granted her own lawyer”.¹⁰²

The ECtHR has also put emphasis on the role of the judge during the legal incapacitation procedure. In *X and Y v. Croatia*, the court ruled that:

“[...] it is the judge and not a physician, albeit a psychiatrist, who is to assess all relevant facts concerning the person in question and his or her personal circumstances. It is the function of the judge conducting the proceedings to decide whether such an extreme measure is necessary or whether a less stringent measure might suffice. When such an important interest for an individual’s private life is at stake a judge has to balance carefully all relevant factors in order to assess the proportionality of the measure to be taken.”¹⁰³

Specifically, the judge must verify that the conclusions of the psychiatrist making the expert assessment of capacity are not arbitrary and hear witnesses in addition to the doctor. Most importantly, it is “for the judge to make any conclusions as regards the issue of divesting [an individual] of her legal capacity”.¹⁰⁴

The need to minimise the risk of arbitrariness necessitates that strict procedural safeguards govern the incapacitation procedure. The ECtHR examined three such safeguards: the expert medical assessment of capacity, the length of the hearing and how informed the applicant was about the procedure. The assessment of an individual’s capacity presented in court is based on an expert medical examination of his or her particular circumstances. This gives rise to procedural issues

⁹⁶ ECtHR, *Winterwerp v. the Netherlands*, No. 6307/73, 24 October 1979, para. 73.

⁹⁷ ECtHR, *X and Y v. Croatia*, No. 5193/09, 3 November 2011, para. 79.

⁹⁸ See, for example: ECtHR, *Winterwerp v. the Netherlands*, No. 6307/73, 24 October 1979, para. 60.

⁹⁹ ECtHR, *Shtukurov v. Russia*, No. 44009/05, 27 March 2008, para. 73.

¹⁰⁰ ECtHR, *Salontaji-Drobnjak v. Serbia*, No. 36500/05, 13 October 2009, para. 127.

¹⁰¹ ECtHR, *D.D. v. Lithuania*, No.13469/06, 14 February 2012, para. 118.

¹⁰² *Ibid.*, para. 124.

¹⁰³ ECtHR, *X and Y v. Croatia*, No.5193/09, 3 November 2011, para. 85.

¹⁰⁴ *Ibid.*, para. 86.



regarding the adequacy and assessment of evidence. In the *H.F. v. Slovakia* case,¹⁰⁵ the ECtHR found a violation of Article 6 because the applicant had not been represented at the first hearing and the psychiatric report, on the basis of which she was deprived of her legal capacity, could not be regarded as 'up-to-date' within the meaning of Recommendation R(99)4.¹⁰⁶ The ECtHR ruled that the domestic courts had not proceeded with necessary diligence and had failed to assemble sufficient evidence to evaluate the capacities of the applicant and prevent ensuing injustices.¹⁰⁷

Several cases have also highlighted the importance of sufficient time to make the medical assessment, as well as for the ECtHR to hear and consider the evidence. In its judgment in *X and Y v. Croatia*, the court noted that the psychiatrist saw X for only 20 minutes, at a time when she was "tired and under the influence of medication".¹⁰⁸ In the *Shtukatur v. Russia* case the ECtHR said that it was "particularly struck by the fact that the only hearing on the merits in the applicant's case lasted ten minutes", considering that this meant the judge had not had direct contact with the person concerned.

In the *X and Y v. Croatia*¹⁰⁹ case, the finding of a violation of Article 6 (1) turned in part on the court's judgment that the applicants had needed more information to be fully informed about the proceedings. Although X had authorised Y, her daughter, to represent her in legal capacity proceedings, the authorities had not informed Y of either the court hearing or of the decision to deprive X of her legal capacity. By not informing X of its decision, the court had also effectively deprived her of the possibility of appeal and thus to have her capacity restored.

The third element of the ECtHR's approach to legal capacity under Article 6 concerns access to court to challenge the removal of legal capacity. While stating that the "right of access to a court is not absolute but may be subject to limitations", the court cautions that "the limitations applied must not restrict or reduce the access left to the individual in such a way or to such an extent that the very essence of the right is impaired" and that "a limitation will not be compatible with Article 6 (1) if it does not pursue a legitimate aim and if there is not a reasonable relationship of proportionality between the means employed and the aim sought to be achieved".¹¹⁰

The ECtHR expanded upon this general principle in a number of cases. In *Shtukatur v. Russia*, the court noted that "full incapacitation was applied for an indefinite period and could not, as the applicant's case shows, be challenged other than through the guardian, who opposed any attempts to discontinue the measure [...]".¹¹¹ In the *Salontaji-Drobnjak v. Serbia* case, both the applicant and his guardian had lodged complaints for the restoration of his legal capacity, but for four years the national authorities had failed to consider them. Moreover, domestic legislation had no provision for periodic judicial review and reassessment of the person's condition. These impediments led the court to conclude that "the very essence of the applicant's right to a court had been impaired", thereby violating Article 6 (1).¹¹² The court reiterated the importance of periodic reviews of an incapacity decision in *Matter v. Slovakia*, recommending "that the domestic authorities establish after a certain lapse of time whether such a measure continues to be justified" and stated that "such a re-examination is particularly justified if the person concerned so requests".¹¹³

In a key case, *Stanev v. Bulgaria*, the ECtHR's ruling clarified its approach to the restoration of legal capacity. The applicant, who was partially deprived of legal capacity, complained that domestic law did not afford him direct access to a court to apply to regain his capacity. In assessing this claim, the court set out its view that:

*"[...] the right to ask a court to review a declaration of incapacity is one of the most important rights for the person concerned since such a procedure, once initiated, will be decisive for the exercise of all the rights and freedoms affected by the declaration of incapacity, not least in relation to any restrictions that may be placed on the person's liberty [...]. The Court therefore considers that this right is one of the fundamental procedural rights for the protection of those who have been partially deprived of legal capacity."*¹¹⁴

The ECtHR went on to conclude that "Article 6 § 1 of the Convention must be interpreted as guaranteeing in principle that anyone who has been declared partially incapable [...] has direct access to a court to seek restoration of his or her legal capacity".¹¹⁵

The ECtHR also referred to the CRPD and "the growing importance which international instruments for the protection of people with mental disorders are now

¹⁰⁵ ECtHR, *H.F. v. Slovakia*, No. 54797/00, 8 November 2005.

¹⁰⁶ Council of Europe, Committee of Ministers (1999), Principle 12 (2). See Section 1.2.3 for further details on the principles set out in the recommendation.

¹⁰⁷ ECtHR, *H.F. v. Slovakia*, No. 54797/00, 8 November 2005, para. 44.

¹⁰⁸ ECtHR, *X and Y v. Croatia*, No. 5193/09, 3 November 2011, para. 87.

¹⁰⁹ *Ibid.*

¹¹⁰ ECtHR, *Salontaji-Drobnjak v. Serbia*, No. 36500/05, 13 October 2009, para. 133.

¹¹¹ ECtHR, *Shtukatur v. Russia*, No. 44009/05, 27 March 2008, para. 90.

¹¹² ECtHR, *Salontaji-Drobnjak v. Serbia*, No. 36500/05, 13 October 2009, para. 134.

¹¹³ ECtHR, *Matter v. Slovakia*, No. 31534/96, 5 July 1999, para. 68.

¹¹⁴ ECtHR, *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012, para. 241. See also: ECtHR, *Kędzior v. Poland*, No. 45026/07, 16 October 2012, para. 89.

¹¹⁵ ECtHR, *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012, para. 245.

attaching to granting them as much legal autonomy as possible".¹¹⁶ It further observed that "there is now a trend at European level towards granting legally incapacitated persons direct access to the courts to seek restoration of their capacity".¹¹⁷

1.2.3. Restriction of legal capacity and the right to private life

ECHR

Article 8 – Right to respect for private and family life

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

Although there is no explicit provision in the ECHR referring to legal capacity, the ECtHR has recognised that the restriction of a person's legal capacity may represent an 'interference' with their Article 8 right to respect for private and family life. This reflects the court's interpretation of Article 8 as securing "to the individual a sphere within which he or she can freely pursue the development and fulfilment of his personality".¹¹⁸

In the *Berková v. Slovakia* case, the applicant, who had a mental health problem, was deprived of legal capacity and placed under guardianship. The domestic courts refused to restore her full legal capacity and required her to wait three years before reapplying for reinstatement. The court ruled that the decision denying the restoration of her full legal capacity "constituted a serious interference with the applicant's right to respect for her private life".¹¹⁹ It reiterated its view from *Shtukatur v. Russia* that the removal of the applicant's legal capacity constituted "interference with the applicant's private life [that] was very serious" and that "[a]s a result of

his incapacitation the applicant became fully dependent on his official guardian in almost all areas of life".¹²⁰

Having established that interference in the exercise of the right to private and family life has occurred as a result of reduced legal capacity, the issue then becomes whether such interference is justified by one of the provisions set out in Article 8 (2). This reflects the court's position that "restrictions on the rights of persons divested of legal capacity, even when they occur in the sphere of their private and family life, are not in principle in contradiction with the requirements of Article 8".¹²¹

The ECtHR has examined a number of the Article 8 (2) provisions, assessing whether they allow for the restriction of legal capacity in particular circumstances. In the *Berková* case, for example, the court ruled that in prohibiting the applicant from making a new application for full legal capacity for three years, domestic courts "pursued the legitimate aim within the meaning of the second paragraph of Article 8 of protecting the rights of the applicant, who was suffering from mental illness, as well as the rights of others".¹²² The court did not, however, consider that interference in the applicant's private life was "necessary in a democratic society" and thus found a violation of the right to privacy.¹²³

In its landmark judgment in *Shtukatur v. Russia*, the ECtHR established that neither an intellectual disability nor a mental health problem alone constituted a reason for legal incapacitation: "the existence of a mental disorder, even a serious one, cannot be the sole reason to justify full incapacitation".¹²⁴ The ECtHR reflected on the threshold that must be met for the full removal of legal capacity to be compliant with Article 8 rights. The court said that "[b]y analogy with the cases concerning deprivation of liberty, in order to justify full incapacitation the mental disorder must be "of a kind or degree" warranting such a measure".¹²⁵

Building on this distinction between degrees of legal capacity limits, the court elaborated on the need for any measures restricting legal capacity to be proportionate to the 'legitimate aims' described in Article 8 (2). It noted that while the Russian Civil Code distinguishes between full capacity and full incapacity, "it does not provide for any 'borderline' situation other than for drug or alcohol addicts". Referring to the principles elaborated in

¹¹⁶ *Ibid.*, para. 244.

¹¹⁷ *Ibid.*, para. 243.

¹¹⁸ European Commission of Human Rights (1981), *Brüggeman and Scheuten v. Germany*, No. 6959/75, 12 July 1977, Decisions and reports 10, p. 115, para. 55. See also: ECtHR, *Shtukatur v. Russia*, No. 44009/05, 27 March 2008, para. 83; and ECtHR, *Sýkora v. the Czech Republic*, No. 23419/07, 22 November 2012, para. 101.

¹¹⁹ ECtHR, *Berková v. Slovakia*, No. 67149/01, 24 March 2009, para. 175.

¹²⁰ ECtHR, *Shtukatur v. Russia*, No. 44009/05, 27 March 2008, para. 90.

¹²¹ ECtHR, *Kruskovic v. Croatia*, No. 46185/08, 21 June 2011, para. 30.

¹²² ECtHR, *Berková v. Slovakia*, No. 67149/01, 24 March 2009, para. 172.

¹²³ *Ibid.*, para. 175.

¹²⁴ ECtHR, *Shtukatur v. Russia*, No. 44009/05, 27 March 2008, para. 94.

¹²⁵ *Ibid.*

Recommendation R(99)4 of the Committee of Ministers, which set out the need for proportionality and the maximum reservation of capacity, the court concluded that a binary distinction between full and no legal capacity does not “provide for a ‘tailor-made response’” as envisaged by the recommendation.¹²⁶ The court went on to conclude that “as a result, in the circumstances the applicant’s rights under Article 8 were limited more than strictly necessary”¹²⁷ and “that the interference with the applicant’s private life was disproportionate to the legitimate aim pursued”,¹²⁸ thereby constituting a violation of Article 8.

ECtHR case law has also considered the balance between individual rights and the wider public interest. In the *Kruskovic v. Croatia* case, the birth registry brought proceedings to annul the applicant’s registration as a father, owing to his restricted legal capacity. In finding a violation of Article 8, the court said that:

“[...] a fair balance has not been struck between the public interest in protecting persons divested of their legal capacity from giving statements to the detriment of themselves or others, and the interest of the applicant in having his paternity of K. legally recognised.”¹²⁹

In addition to considering whether restrictions of legal capacity are justified under Article 8 (2), the ECtHR’s approach has focused on the time taken for the relevant domestic authorities to make decisions regarding an individual’s legal capacity. In the *Kruskovic* case, the court noted that “the relevant national authorities instituted the court proceedings for the establishment of the applicant’s paternity only more than two and half years after the applicant had requested them to do so, thus allowing a situation to arise in which the claim by the applicant and the child’s mother that the applicant was the biological father of K. was ignored for no apparent reason”.¹³⁰ This left the applicant in a “legal void”.¹³¹ The issue of time was also specifically invoked in the *Berková* case ruling. Noting domestic concerns that the “three-year period during which a person could be prohibited from re-applying for restoration of their legal capacity was excessively long and capable of seriously affecting such a person’s human rights”,¹³² the court concluded that the violation of Article 8 in the case was the result of “the applicant’s being prohibited from re-applying for restitution of full legal capacity for a period of three years”.¹³³

¹²⁶ *Ibid.*, para. 95.

¹²⁷ *Ibid.*

¹²⁸ *Ibid.*, para. 96.

¹²⁹ ECtHR, *Kruskovic v. Croatia*, No. 46185/08, 21 June 2011, para. 42.

¹³⁰ *Ibid.*, para. 43.

¹³¹ *Ibid.*, para. 40.

¹³² ECtHR, *Berková v. Slovakia*, No. 67149/01, 24 March 2009, para. 174.

¹³³ *Ibid.*, para. 176.

1.2.4. Common safeguards

The Council of Europe Committee of Ministers adopted Recommendation R(99)4 on 23 February 1999, providing significant guidance on legal capacity and guardianship procedures. It predates the CRPD’s adoption by several years, and therefore also the standards set out in Article 12 of the CRPD. However, while the European standards are bound to evolve in the light of the CRPD, the Rec(99)4 standards remain the most detailed at European level and continue to guide the ECtHR. Recommendation R(99)4 applies to “adults who, by reason of an impairment or insufficiency of their personal faculties, are incapable of making, in an autonomous way, decisions concerning any or all of their personal or economic affairs, or understanding, expressing or acting upon such decisions, and who consequently cannot protect their interests”.¹³⁴ Setting out important principles such as necessity and subsidiarity, flexibility and proportionality, the recommendation stipulates safeguards that should be in place before a decision on legal capacity can be taken. These principles promote common action and standards among Council of Europe member states.

Council of Europe Committee of Ministers Recommendation R(99)4

Principle 5 – Necessity and subsidiarity

1. No measure of protection should be established for an incapable adult unless the measure is necessary, taking into account the individual circumstances and the needs of the person concerned. [...]
2. In deciding whether a measure of protection is necessary, account should be taken of any less formal arrangement which might be made, and of any assistance which might be provided by family members or by others.

Part two of the recommendation sets out 10 ‘governing principles’ regarding the legal protection of incapable adults. These establish core safeguards and considerations that should be in place, and which must be met before a person can lawfully be deprived of their legal capacity. It says, for example, that any measure should be necessary, proportional to the person’s capacity and tailored to their individual circumstances and needs, and sufficiently flexible to enable a suitable response to different degrees of incapacity and various situations.¹³⁵ In the establishment of the protective measure, the person’s “interests and welfare” should be the paramount consideration, and their “past and present wishes and feelings” should be

¹³⁴ Council of Europe, Committee of Ministers (1999), Part 1 (1).

¹³⁵ *Ibid.*, Principles 5, 6 and 8.

“ascertained so far as possible, and should be taken into account and given due respect”.¹³⁶

Council of Europe Committee of Ministers Recommendation R(99)4

Principle 6 – Proportionality

1. Where a measure of protection is necessary it should be proportional to the degree of capacity of the person concerned and tailored to the individual circumstances and needs of the person concerned.
2. The measure of protection should interfere with the legal capacity, rights and freedoms of the person concerned to the minimum extent which is consistent with achieving the purpose of the intervention.

Significantly, the recommendation introduces a maximum preservation of capacity clause in Principle 3, which calls on states to ensure that their legal frameworks “so far as possible recognise that different degrees of incapacity may exist and that incapacity may vary from time to time”. As such, “a measure of protection should not result automatically in a complete removal of legal capacity”, although “a restriction of legal capacity should be possible where it is shown to be necessary for the protection of the person concerned”.¹³⁷ In this way, Recommendation R(99)4 reconceives the relationship between legal capacity and subsequent loss of decision-making ability, recommending that no measure should “automatically deprive the person concerned of the right to vote, or to make a will, or to consent or refuse consent to any intervention in the health field, or to make other decisions of a personal character at any time when his or her capacity permits him or her to do so”.¹³⁸

Council of Europe Committee of Ministers Recommendation R(99)4

Council of Europe Committee of Ministers Recommendation R(99)4

Principle 3 – Maximum preservation of capacity

1. The legislative framework should, as far as possible, recognize that different degrees of incapacity may exist and that incapacity may vary from time to time. Accordingly, a measure of protection should not result automatically in a complete removal of legal capacity. However, a restriction of legal capacity should be possible where it is shown to be necessary for the protection of the person concerned.
2. In particular, a measure of protection should not automatically deprive the person concerned of the right to vote, or to make a will, or to consent or refuse consent to any intervention in the health field, or to make other decisions of a personal character at any time when his or her capacity permits him or her to do so.

Paragraphs three and four of Principle 3 offer further detail on how the maximum preservation of capacity can be ensured. Here the recommendation calls for legal arrangements to allow individuals under guardianship, with their guardian’s consent, to undertake specific acts or acts in a specific area, and notes that “wherever possible the adult should be enabled to enter into legally effective transactions of an everyday nature”.

Moreover, the recommendation introduces the possibility of elements of supported decision-making later elaborated in the CRPD. Principle 5 (2) asks states to take account of any “less formal arrangements” which could be made and of “any assistance which may be provided by family members or by others”. This reflects the recommendation in Principle 2 for measures of protection that “do not restrict the legal capacity of the person concerned”¹³⁹ and “are limited to one specific act without requiring the appointment of a representative or a representative with continuing powers”.¹⁴⁰

¹³⁶ *Ibid.*, Principles 8 and 9 (1).

¹³⁷ *Ibid.*, Principle 3 (1).

¹³⁸ *Ibid.*, Principle 3 (2).

¹³⁹ *Ibid.*, Principle 2 (4).

¹⁴⁰ *Ibid.*, Principle 2 (5).

Once the basic principles that allow the restriction or removal of legal capacity are met, the key issue becomes the procedures surrounding the incapacity decision and the scope for appeal. In conjunction with some of the general principles, the recommendation's procedural principles elaborate on the safeguards that should be in place when instigating a protective measure. Principle 7 on the fairness and efficiency of legal incapacity procedures calls for "adequate procedural safeguards to protect the human rights of the persons concerned and to prevent possible abuses".

Council of Europe Committee of Ministers Recommendation R(99)4

Principle 14 – Duration, review and appeal

1. Measures of protection should, whenever possible and appropriate, be of limited duration. Consideration should be given to the institution of periodical reviews.
2. Measures of protection should be reviewed on a change of circumstances and, in particular, on a change in the adult's condition. They should be terminated if the conditions for them are no longer fulfilled.
3. There should be adequate rights of appeal.

This call is reflected in a general safeguard clause, set out in Principle 14. Measures of protection should be of limited duration, and Member States should consider instituting periodic reviews and provide for the right of appeal. If circumstances change, the protective measure should be reviewed and terminated if the conditions justifying it no longer exist. The Explanatory Memorandum to Recommendation R(99)4 reiterated this position, saying that "measures of protection should not be established for an indefinite duration unless this is necessary or appropriate in the interests of the adult concerned", such as in cases of dementia "from which there is not possibility of recovery".¹⁴¹ The Explanatory Memorandum also indicates that national law should determine who can demand a review of protective measures, and should include the adult concerned.¹⁴²

Council of Europe Committee of Ministers Recommendation R(99)4

Principle 12 – Investigation and assessment

1. There should be adequate procedures for the investigation and assessment of the adult's personal faculties.
2. No measure of protection which restricts the legal capacity of an incapable adult should be taken unless the person taking the measure has seen the adult or is personally satisfied as to the adult's condition and an up-to-date report from at least one suitably qualified expert has been submitted. The report should be in writing or recorded in writing.

Principle 13 – Right to be heard in person

The person concerned should have the right to be heard in person in any proceedings which could affect his or her legal capacity.

Part three of Recommendation R(99)4 elaborates on some of these safeguards, namely the right to proper assessment of capacity, the involvement of the person concerned and review of the incapacity decision. It requires Council of Europe member states to ensure that persons subject to legal incapacity proceedings: are informed promptly in a form they understand of the institution of legal capacity proceedings;¹⁴³ are guaranteed adequate procedures for the investigation and assessment of their faculties, including that those taking the measure see those concerned or a suitably qualified expert submits an up-to-date report;¹⁴⁴ and are able to exercise the right to be heard in person in any proceedings affecting their legal capacity.¹⁴⁵ Finally, Principle 14 provides for "adequate rights of appeal".

Recommendation R(99)4 also offers guidance relating to the person chosen to represent a person deprived of their legal capacity, which in most cases is a guardian: the choice of guardian should be "governed primarily by the suitability of that person to safeguard and promote the adult's interests and welfare",¹⁴⁶ and the decision should be taken after the wishes of the adult "as to the choice of any person to represent or assist" them have been accounted for and "as far as possible, given due respect".¹⁴⁷ This, in turn, requires that the guardian gives the person under guardianship adequate information concerning any major decisions so that he or she may express a view. In

¹⁴³ Council of Europe, Committee of Ministers (1999), Principle 11.

¹⁴⁴ *Ibid.*, Principle 12.

¹⁴⁵ *Ibid.*, Principle 13.

¹⁴⁶ *Ibid.*, Principle 8.

¹⁴⁷ *Ibid.*, Principle 9 (2).

¹⁴¹ *Ibid.*, Explanatory memorandum, para. 56.

¹⁴² *Ibid.*

addition, part four of the recommendation on the role of representatives sets out a number of procedural safeguards and areas where national law must determine the scope of a guardian's power.

Part five of Recommendation R(99)4 sets out safeguards regulating interventions in the health field. Principle 22 states that when adults, "even if subject to a measure of protection", are capable of providing their free and informed consent to a given intervention in the health field, then the intervention may be carried out with their consent. If an adult is not capable of giving free and informed consent, "the intervention may, nonetheless, be carried out provided that: it is for his or her direct benefit; and authorisation has been given by his or her representative or by an authority or a person or body provided for by law". This approach was subsequently echoed by Recommendation Rec(2004)10, which sets out standards related to the protection of the rights of persons with mental disorders. Article 12 of Rec(2004)10 states that "treatment may only be provided to a person with mental disorder with his or her consent if he or she has the capacity to give such consent, or, when the person does not have the capacity to consent, with the authorisation of a representative, authority, person or body provided for by law".¹⁴⁸ These recommendations should be read in conjunction with Articles 5 to 7 of the Oviedo Convention.¹⁴⁹

In 2009, the Committee of Ministers adopted another instrument, Recommendation Rec(2009)11, on planning for future incapability.¹⁵⁰ It recommends that states adopt legislation to ensure that people can appoint a continuing power of attorney, defined as "a mandate given by a capable adult with the purpose that it shall remain in force, or enter into force, in the event of the granter's incapacity".¹⁵¹ Such a measure should cover "economic and financial matters, as well as health, welfare and other personal matters [...]".¹⁵² The 2009 Recommendation also sets out the advantages of making available advance directives – "instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity"¹⁵³ – which "may apply to health, welfare and other personal matters, to economic and financial matters, and to the choice of a guardian, should one be appointed".¹⁵⁴

Furthermore, the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society, which runs from 2006 to 2015, explicitly refers to the legal protection of the right to legal capacity of persons with disabilities. It aims to ensure that persons with disabilities have effective access to justice on equal basis with others and that they are afforded appropriate assistance in exercising their legal capacity.¹⁵⁵

¹⁴⁸ Council of Europe, Committee of Ministers (2004), Art. 12.

¹⁴⁹ Council of Europe (1997).

¹⁵⁰ Council of Europe, Committee of Ministers (2009b).

¹⁵¹ *Ibid.*, Principle 2 (1).

¹⁵² *Ibid.*, Principle 3.

¹⁵³ *Ibid.*, Principle 2 (3).

¹⁵⁴ *Ibid.*, Principle 14.

¹⁵⁵ Council of Europe, Committee of the Ministers (2006), see respectively 3.12.2(i) and 3.12.3.(vi).



2

The right to legal capacity in EU Member States

“Many European States have outdated laws which are incompatible with Article 12 of the CRPD, according to which there should be supported decision-making, not substituted decision-making as we still see in a number of European countries. Substituted decision-making with plenary guardianship makes it impossible for many with intellectual or psychosocial disabilities to access any justice at all, as they are represented in all procedures by a guardian whom they may not even know and who simply takes bureaucratic decisions – including about vital issues such as admission into an institution – on their behalf. I call on all European States to change such anachronistic laws with no delay, and to ensure that their legislation is fully in line with Article 12 of the CRPD.”

Statement by Navi Pillay, United High Commissioner for Human Rights at the FRA Fundamental Rights Conference 2012, Brussels, 6 December 2012

Article 12 of the CRPD has prompted an on-going re-examination of the concept of legal capacity of persons with disabilities. The CRPD Committee has commented on restricting the legal capacity of persons with disabilities in all six concluding observations issued to date.¹⁵⁶ Despite the diversity of legal capacity legislations scrutinised, the CRPD Committee has clearly set the replacement of substituted decision-making with supported decision-making as a prerequisite for the fulfilment of Article 12 of the CRPD.

Nevertheless, because the CRPD Committee has yet to provide an authoritative interpretation of Article 12 in a general comment, this chapter uses the standards and principles laid down by Council of Europe Recommendation Rec(99)4 as an analytical framework. Although the recommendation predates the CRPD and should therefore be reassessed, it nevertheless sets out important principles and safeguards, which provide common standards for Council of Europe member states. It also provides a useful analytical tool to examine current EU Member

States’ national legislation because it sets out the main procedural processes and criteria involved in decision-making on the legal capacity of persons with disabilities and the roles of different actors in the proceedings.

This chapter provides an overview of legal capacity and guardianship laws, and on-going reform efforts, in the 27 EU Member States as of 2012, analysing in particular recent reforms in Member States that are moving towards supported decision-making from substituted decision-making.

When discussing legal capacity, two closely related terms often occur in national legal frameworks: ‘capacity’ and ‘competence’. In some cases they are used interchangeably, in others they have different meanings. This report does not look at the issue of a person’s ‘competence’ to stand trial and focuses on the recognition of persons with disabilities before the law on equal basis with others.

Before embarking on the legal analysis, it is also crucial to highlight the difference between loss of legal capacity and introduction of a protective measure. In this discussion, when reference is made to the introduction of a protective measure, it refers only to placement under guardianship and not to the loss of the person’s legal capacity. ‘Guardianship’ is moreover understood as ‘substituted decision-making’, in the sense that the guardian is legally entitled to make decisions on behalf of the person placed under a protective measure.

2.1. National legal frameworks

All EU Member States have a legal framework that regulates the process leading to a restriction of a person’s legal capacity, although the majority of these frameworks are old, FRA research shows. In **Ireland**,

¹⁵⁶ Since the entry into force of the CRPD, the CRPD Committee adopted six concluding observations on Hungary and Spain, and Argentina, China, Peru and Tunisia.

for example, the Lunacy Regulation Act dates to 1871, while **Romania's** legal framework has been in force since the 1950s. Legal capacity laws in **Slovakia** and **Poland** took effect in 1964. (For a full overview of the national frameworks and last significant amendments regulating legal capacity in the EU-27, see Annex 1.)

Higher national courts, however, have acknowledged the need for reform to move to more tailored approaches and less restrictive interference. In 2007, the **Polish** Constitutional Court, for example, acknowledged that the rights of legally incapacitated persons should be better respected. It recommended: models of institutional solutions of assistance and flexible care instead of incapacitation, which results in deprivation or limitation of capacity to undertake legal actions; and increased safeguards for persons divested of legal capacity.¹⁵⁷

More recently, on 27 December 2010, the Constitutional Court of **Latvia** ruled that Articles 358 and 364 of the Civil Code do not conform with the Latvian Constitution, because they unreasonably restrict a person's right to a private life since the only option to deprive a person of their legal capacity was to impose a full deprivation of legal capacity. The court based its reasoning on Latvia's international human rights obligations and noted that a person's legal capacity should be restricted only to the degree necessary. The court also said that "[...] in order to implement Article 12 of the [CRPD], amendments must be made to the Civil Law, the Civil Procedure Law and the Law on Orphan's Courts, prohibiting full restriction of legal capacity"¹⁵⁸ and concluded that the disputed norms shall be invalid from 1 January 2012.¹⁵⁹ Consequently, on 29 November 2012, the Latvian parliament adopted extensive amendments abolishing plenary guardianship and introducing revisions to all relevant aspects of the national framework.¹⁶⁰

Several EU Member States have acknowledged that they need to harmonise their legislation with current international and European standards and some have recently reviewed their national legislative framework on legal capacity, such as **England and Wales** (2005), **France** (2007) and **Germany** (2009). **Sweden** abolished

total guardianship in 1989. Following CRPD ratification, the EU-27 have adopted or initiated new legislation and policies. The **Czech Republic** reformed its legislation and a new Civil Code will enter into force on 1 January 2014. Likewise, the **Hungarian** parliament amended legal capacity provisions dating back to 1959 with a new Civil Code that is expected to enter into force on 1 January 2014.

In addition, legislative changes appear to be under way in a number of countries. In **Malta**, the Civil Code was amended in December 2012¹⁶¹ to introduce a system of guardianship providing that "a major who has a mental disorder or other condition which renders him incapable of taking care of his own affairs may be subject to guardianship".¹⁶² The **Finnish** Ministry of Social Affairs and Health appointed a working group in July 2010 to draft a reform of the provisions governing restrictions to self-determination of clients in social services and health care. The term of the working group has been extended until the end of 2013, by which time it is expected to have finalised a proposal for a government bill.¹⁶³

Bulgaria ratified the CRPD on 26 January 2012, just a few days after the Grand Chamber of the ECtHR issued its judgment in the *Stanev v. Bulgaria* case.¹⁶⁴ The two events prompted the Ministry of Justice to form a working group composed of experts from the Ministries of Justice and Labour and Social Policy, as well as representatives of NGOs and academia. The working group is to reform legal capacity provisions in line with Article 12 of the CPRD. It published a concept paper that envisages the abolition of plenary guardianship and the adoption of alternative measures such as advanced directives and supported decision-making. The concept paper also stipulates that protection measures should be based on the principles of necessity, proportionality, flexibility, respect for the will of the person and periodic review

¹⁵⁷ Poland, Constitutional Tribunal, Judgment K 28/05, 7 March 2007, available at: www.e-include.eu/en/legal-network-news/legal-capacity/120-important-judgments-of-the-polish-constitutional-tribunal-on-the-issue-of-legal-incapacitation. See also: ECtHR, *Kędzior v. Poland*, No. 45026/07, 16 October 2012, para. 39 and 80, which refer to the Constitutional Court decision.

¹⁵⁸ Latvia, Constitutional Court, No. 2010-38-01, 27 December 2010, available in English at: <http://zelda.org.lv/en/news/the-constitutional-court-of-latvia-has-adopted-a-decision-in-rc-zelda-clients-j-f-cas-493>.

¹⁵⁹ See also: ECtHR, *Mihailovs v. Latvia*, No. 35939/10, 22 January 2013, para. 79 and 157, which refer to the Constitutional court decision.

¹⁶⁰ See: Latvia, Amendments to the Civil Law, 29 November 2012, available in Latvian at: www.likumi.lv/doc.php?id=253623.

¹⁶¹ Malta, House of Representatives (2012), *XXIV of 2012 – Code of Organization and Civil Procedure and the Civil Code (Amendment) Act*, Government Gazette of Malta No. 18,999, 7 December 2012, Art. 188A, available at: <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=24286&l=1>.

¹⁶² Malta, Civil Code, Chapter 16 of the Laws of Malta, Art. 188A.

¹⁶³ Finland, Finnish Government's register of projects (*Valtioneuvoston hankerekisteri, HARE/Statrådets project register*), available in Finnish at: www.hare.vn.fi/mHankePerusSelaus.asp?h_id=16727&tVNo=1&Typ=Selaus.

¹⁶⁴ For more information on the judgment please see Section 1.2.2.



and should aim at avoiding conflicts of interests.¹⁶⁵ Ireland¹⁶⁶ and Poland¹⁶⁷ have similar developments under way.

Essential Principles: Irish Legal Capacity Law

A group of NGOs developed and issued 10 key principles to guide the Irish government in updating legal capacity legislation. The law should reflect autonomy, self-determination, respect for the person's expression of "will and preferences". It should always respect a person's fundamental rights and put strict safeguards in place to ensure that respect. The information and processes relating to supportive decision-making must be easy to understand and meet the person's needs; an independent decision-making body is preferred to a court-based system which cannot provide an individualised response.

Based on this and other written and oral submissions made on the proposed mental capacity bill, the Joint Committee on Justice, Defence and Equality of the Irish national parliament (*Oireachtas*) issued a report in May 2012 with its observations on the proposed legislation. The report concludes that "[a] human rights-based approach to legal capacity is not currently prevalent" and that "[the] present legal framework on capacity derives from legislation in the 19th Century [...] and is totally inadequate to meet modern standards. It is also insufficient to meet [Ireland's] international commitments under the UN Treaty on the Rights of Persons with Disabilities which was signed by Ireland in 2007."

Source: *The Joint Committee on Justice, Defence and Equality report on the Mental Capacity Bill (May 2012)* available at: www.oireachtas.ie/parliament/mediaszone/pressreleases/name-7795-en.html. For the discussions on the Mental Capacity Legislation, 29 February 2012, see: <http://debates.oireachtas.ie/JU/2012/02/29/00004.asp>

2.1.1. Degrees of legal capacity deprivation and protective measures

While the CRPD signposts the path away from the guardianship model, EU Member State legislative frameworks regulating legal capacity currently diverge from this model, with a diversity of types and degrees of legal incapacity measures and corresponding safeguards.

Persons with intellectual disabilities and mental health problems could have their legal capacity deprived or restricted under the institution of a protective measure, for example placement under guardianship; the guardian is then responsible for taking decisions for that person in order to manage that person's affairs.

The protective measure of guardianship can be applied in almost all EU Member States. Council of Europe Recommendation R(99)4 requires the maximum preservation of capacity (Principle 3) and the proportionality of the measure (Principle 6), informing member states that "[t]he measure of protection should interfere with the legal capacity, rights and freedoms of the person concerned to the minimum extent which is consistent with achieving the purpose of the intervention".¹⁶⁸ The FRA analysis shows that there are two typical models of legal capacity deprivation which correspond to full or plenary guardianship and to partial guardianship. In case of total deprivation of legal capacity, full guardianship is instituted and a representative is appointed. In case of partial loss of legal capacity, guardianship will be instituted only for those matters for which legal capacity has been restricted.

The relevant laws across the EU Member States vary considerably in the terminologies they use, making comparisons challenging. Systems that use substituted decision-making schemes, or full loss of legal capacity, may term such representation as full guardianship, 'wardship' (in Ireland) or 'tutorship' (in France and Luxembourg (*tutelle*) and in Italy (*tutore*)). The term 'curatorship' appears to be used in Estonia, France, Luxembourg, Portugal and Spain to refer to various systems of partial restriction of legal capacity, and systems under which the legal representative can make legally binding decisions only with the agreement or consent of the person concerned. In contrast, the Dutch 'curator' (*curatele*) system is the most restrictive, with a person under such a system requiring the curator's permission for all legal acts.

¹⁶⁵ Bulgaria, Ministry of Justice, Draft concept of amendments of the national legislation relating to the implementation of the standards set by Article 12 of the UN Convention on the Rights of Persons with Disabilities (*Проект на Концепция за промени на националното законодателство, свързани с прилагането на стандартите на чл.12 на Конвенцията на ООН за правата на хората с увреждания*), 11 October 2012, available in Bulgarian at: www.strategy.bg/PublicConsultations/View.aspx?lang=bg-BG&Id=716.

¹⁶⁶ Ireland, The Law Reform Commission: Consultation Paper on Vulnerable Adults and the Law: Capacity, Dublin, May 2005, available at: www.lawreform.ie/_fileupload/consultation%20papers/Consultation%20Paper%20on%20Capacity.pdf.

¹⁶⁷ Poland, Text of the position of the President of Codification Commission of Civil Law available at: www.hfhrpol.waw.pl/precedens/images/stories/odpowiedz_KKPC.pdf.

¹⁶⁸ Council of Europe, Committee of Ministers (1999), Principle 6, para. 2. For more information, see: Section 1.2.4.

Legal capacity terminology in some EU Member States

Sweden:

Trustee (*förvaltare*): appointed by the court as the person's guardian. A trustee does not need consent from the person with a disability to make a legally binding decision.

Mentor (*god man*): assists the person with a disability in legal and other matters, but the individual must give his or her consent before legally binding actions are taken. The decision to have a mentor is voluntary, but the district court can appoint one if, owing to health problems, the individual is unable to take a decision him- or herself.

France:

Curator (*curateur*): helps the person with the management of their income (paying the bills) but does not prevent people from assuming other social roles. The measure affects the management of the person's assets and marriage, but not his or her capacity to receive income or to pay ordinary expenses. There are two types of curatorship: the simple curatorship (*curatelle simple*) and the intensified curatorship (*curatelle renforcée*). In the second case, the curator decides on the use of the person's income, and generally allocates the person a weekly sum.

Tutor (*tuteur*): can replace the person in decision-making for every important daily activity. The level of protection covers both the person and his or her assets. Tutorship is taken up whenever it is deemed necessary to use a measure of protection. The person who is under tutorship is considered to be judicially incapable.

Note: These terms are not an exhaustive list of the different words and phrases used in EU Member States to describe a person empowered to take decisions on another's behalf, and reflect some of the terms used by participants in FRA's fieldwork research (see Chapter 3)

The findings of the FRA legal analysis show that the majority of EU Member States have adopted different degrees of legal capacity restriction, aiming at instituting measures which are proportional and reflect the individual's situation. Others provide alternatives to plenary and partial guardianship by establishing other support mechanisms. The legal frameworks in a very few Member States do not recognise different degrees of deprivation of legal capacity and provide only for full, or plenary, guardianship, for example in **Cyprus, Ireland** and **Romania**. Finally, two EU Member States, **Germany** and **Sweden**, have abolished their guardianship systems as a protective measure and put other, less intrusive, forms in place.

A few examples will illustrate the situation across the 27 EU Member States.

Slovakia,¹⁶⁹ **Slovenia**¹⁷⁰ and **Poland**¹⁷¹ have two degrees of restriction – either for all legal acts or just for certain legal acts – which reflect the two models of guardianship. The old **Hungarian** Civil Code of 1959 also stipulated such a division between two degrees of legal capacity deprivation.¹⁷² The CRPD Committee expressed its concern in its Concluding Observations on the Hungarian State Report that the drafting of the new Civil Code has not been used to provide for a detailed and viable framework for supported decision-making in accordance with Article 12 of the CRPD. Instead, the draft Civil Code, enacted in July 2012, still makes it possible to maintain a modified regime of substituted decision-making resulting in full deprivation of legal capacity.¹⁷³ The legal acts affected by restriction of a person's legal capacity include applying for social security, unemployment and other benefits; disposition with income from these benefits or from employment relationships; and disposition with movable and immovable property and family-law-related legal actions.¹⁷⁴

Some EU Member States offer a wider variety of guardianship options. In **Austria**, for example, guardianship could be limited to a single issue, or, most commonly, to several matters or, indeed, all matters.¹⁷⁵ Similarly, the **Greek** legal system provides for several guardianship measures, which differ in intensity: guardianship depriving the person of capacity for some (partial) or all (total) legal transactions; and guardianship whereby legal transactions of the person become valid only when coupled with the guardian's consent. The court can also opt for a combination of the two regulations.¹⁷⁶

The legal frameworks in another group of Member States also provide for alternatives to plenary or partial guardianship. To take just a few examples, in **Belgium**, it is possible to appoint a 'counsellor' (*conseil judiciaire/ raadsman*), who is a person designated to assist the person with disability only in those actions specified by law. When the person placed under this protective measure acts without the assistance of the 'counsellor', his or her decisions have no legal effect.¹⁷⁷ Another possibility is the appointment of a 'provisional administrator' (*administrateur provisoire/voorlopige bewindvoerder*),

¹⁶⁹ Slovakia, Civil Code, 26 February 1964, Art. 10.

¹⁷⁰ Slovenia, Non-litigious Civil Procedure Act, Art. 44.

¹⁷¹ Poland, Civil Code, Art. 13 (2) and Art. 16 (2).

¹⁷² Hungary, Act IV of 1959 on the Civil Code of the Republic of Hungary, 11 August 1959, Art. 14 (4) and (5).

¹⁷³ Available in Hungarian at: www.kormany.hu/download/o/d7/70000/%C3%9Aj%20Polg%C3%A1ri%20T%C3%B6rv%C3%A9nyk%C3%B6nyv%20-%20a%20Kodifik%C3%A1ci%C3%B3s%20F%C5%91bizotts%C3%A1g%20javaslata%20-%20k%C3%B6zz%C3%A9t%C3%A9telre.pdf.

¹⁷⁴ Hungary, Act IV of 1959 on the Civil Code of the Republic of Hungary, 11 August 1959, Art. 14 (6).

¹⁷⁵ Austria, Civil Code, Section 268 (3).

¹⁷⁶ Greece, Civil Code, Art. 1676.

¹⁷⁷ Belgium, Judicial Code, Art. 1247.

who manages the person's assets and represents the protected person in all lawsuits concerning assets and some personal acts.¹⁷⁸ Likewise, the **Dutch** Civil Code contains three general procedures: 'protective trust' (*bewindvoering*), aimed at protecting the property and financial interests of the person; 'mentorship' (*mentorschap*), aimed at protecting the interests of the patient regarding care and treatment; and full guardianship (*curatele*), aimed at protecting property and financial interests and/or interests regarding care and treatment. In all three of these cases the court appoints a person whose task it is to act on behalf of the person placed under the protective measure. Of these three possibilities, full guardianship is seen as a legal measure of last resort as it most sharply curbs the person's scope for decision-making, requiring the curator's permission for all legal acts.¹⁷⁹

A small number of EU Member States provide only for full deprivation of legal capacity in their legal framework, yet even here there are developments. In **Romania**, for instance, the law provides only for the total deprivation of capacity, called interdiction (*interdiction*).¹⁸⁰ A person placed under interdiction is no longer entitled to exercise his or her rights, to make legal claims or to conclude legal acts; only the court-appointed guardian may take on these activities on behalf of the person. Similarly, the **Irish** Ward of Court system hands a person's decision-making over to the court, currently the only mechanism for managing the affairs of persons deemed as lacking decision-making capacity.

In **Latvia**, until recently, the legal framework provided only for total deprivation of legal capacity. Amendments to the law, which entered into force on 1 January 2013, abolished full guardianship and introduced several other forms of supported/partly substituted decision-making.¹⁸¹

By abolishing guardianship, **Germany** and **Sweden** have allowed the individual to retain a certain degree of legal capacity. **Germany** replaced such guardianship with custodianship (*Betreuung*) in 1992, whose most important feature is that the person under custodianship maintains his or her right to self-determination to the greatest degree possible. The appointment of a custodian does not automatically restrict a person's legal capacity and contractual ability, such as the right to marry, to make a will or to be granted parental custody. If a person with an intellectual disability or mental health problems needs help merely with household tasks, for example, then a legal representative need not be appointed.

¹⁷⁸ Belgium, Civil Code, Art. 488bis.

¹⁷⁹ Netherlands, Civil Code. See: Title 19, Art. 431, on protective trust; Title 20, Art. 450, on mentorship and Title 16, Arts. 378–391, on full guardianship.

¹⁸⁰ Romania, Civil Code as amended by Law 287/2009, Art. 164.

¹⁸¹ Latvia, Amendments to the Civil Law, 29 November 2012.

Promising practice

Accessing patients' rights

Sweden launched the innovative Personal Ombudsmen (*personligt ombud*) system with its psychiatric reform in 1995. It began as a pilot programme to deal with the previous system's deficiencies and combat patients' inability to access their rights. A Personal Ombudsman (PO) is a skilled professional independent of other authorities with a user-centred attitude, whose role is to reach out to persons who are often left unassisted and do not have access to support. The PO acts in the service of a person with a mental health problem, in other words, only upon client request, and therefore generally develops a close and trusting relationship with him or her. Since it takes time to establish such a relationship, the PO is expected to support the person with a mental health problem for several years. The client discusses their situation with the PO and they jointly decide upon the type of support to be provided, which is a clear manifestation of the trend towards supported decision-making tailored to a person's needs. The POs usually provide support with the person's representation when dealing with the healthcare system and other agencies.

For more information, see:
[www.po-skane.org/The_Swedish_Personal_ombudsmen_system\(Maths_Comments\).php](http://www.po-skane.org/The_Swedish_Personal_ombudsmen_system(Maths_Comments).php)

Sweden replaced guardianship with two alternative measures of assistance in January 1989. If a person needs help managing his or her affairs because of mental or physical ill health, for example, the court can appoint a mentor (*god man*) or trustee (*förvaltare*). A curator offers assistance without limiting the individual's legal capacity to act. A trustee, in contrast, is appointed when an individual is unable to take care of him- or herself or his or her property; a trustee does not need consent from the person with a disability to take a legally binding decision. The trustee's mandate stipulates the concrete restrictions to legal capacity.¹⁸²

2.2. Deprivation of legal capacity

Persons with intellectual disabilities and persons with mental health problems can be totally or partially deprived of their legal capacity in all but two EU Member States, as described in Section 2.1. Council of Europe Recommendation Rec(99)4 urges member states to "[...] recognize that different degrees of incapacity may exist and that incapacity may vary from time to

¹⁸² Sweden, Code on Parenthood and Guardianship (SFS: 1949:381), Chapter 11, Art. 7.

time. Accordingly, a measure of protection should not result automatically in the removal of legal capacity”.¹⁸³ In addition, the procedure resulting from the person’s deprivation of legal capacity should be fair and efficient while, at the same time, adequate procedural safeguards should be in place in order to prevent possible abuses.¹⁸⁴

FRA research shows that the procedure followed for depriving a person of his or her legal capacity does not differ much across the EU. Likewise, most EU Member States prescribe similar criteria in national law for restricting legal capacity, though they use diverse definitions. Generally, these require a medical examination upon which a medical certificate declaring a person’s (in)capacity to manage his or her own affairs is based. Based on this certificate, the competent national court issues a judgment with the degree to which a person’s legal capacity has been restricted. The same or a second judgment institutes a protective measure and appoints a guardian.

2.2.1. Statutory criteria for instituting legal incapacity measures

The criteria determining, and the definitions that help trigger, loss of legal capacity vary across the EU Member States. Many national frameworks provide definitions which are not too restrictive and may include a variety of intellectual disability and mental health-related causes. Generally, in most EU Member States, conditions such as a temporary loss of mental faculties or unconsciousness resulting from intoxication or hypnosis do not meet the standard required for imposing a restriction to or loss of legal capacity. Nor does the emergence of an intellectual disability or a mental health problem automatically lead to legal incapacity in most EU Member States. The element of a certain medical condition, for which the terms vary widely, is usually coupled with a second criterion, which refers to the individual’s ‘inability’, ‘incompetency’ or ‘lost capacity’ to manage his or her affairs.¹⁸⁵ A person’s legal capacity is restricted and a guardian is appointed only when this second element is also present.

FRA’s analysis shows that several EU Member States refer to the causes leading to legal incapacitation in broad terms. **Italian** law, for example, refers to ‘mental infirmity’ or ‘psychic impairments’.¹⁸⁶ **Spanish** law states “diseases or lasting physical or mental deficiencies that

prevent a person from managing his/her own affairs are deemed to be grounds for incapacity”.¹⁸⁷ As criteria for appointing a guardian, Section 8 (1) of the **Finnish** Guardianship Services Act speaks of “illness, disturbed mental faculties, diminished health or other comparable reasons” and stipulates that the person’s interests must also be at risk. There is therefore no predetermined exhaustive enumeration of causes. The determination must be done by examining the ‘mental deficiency’ of each person, its lasting character and the degree to which the capacity for self-determination is lost.

The Mental Capacity Act 2005 in **England and Wales** sets out a broad definition: “a person [who] lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or disturbance in the functioning of, the mind or brain.”¹⁸⁸ In **Scotland** and in **Northern Ireland**, with regards to the management of property and affairs, the term used, ‘mental disorder’, includes mental health problems and intellectual disability and, in **Scotland**, personality disorders.¹⁸⁹

The analysis shows that in a few EU Member States the condition which may lead to legal incapacity must be of a ‘permanent’ nature.¹⁹⁰ This means that either the mental health-related causes or the inability to understand one’s affairs must be enduring and unchanging. Article 489 of the **Belgian** Civil Code stipulates, for example, that for a person to be declared incompetent, he or she must be in a “permanent state of stupidity or insanity”;¹⁹¹ similar provisions can be found in **Cyprus**, **Germany**, **Romania** and **Slovakia**.¹⁹² Another example is **Estonia**, where legislation requires three conditions to be met: the person is an adult; has a mental illness or mental

¹⁸⁷ Spain, Civil Code, Art. 200.

¹⁸⁸ United Kingdom (England and Wales), Mental Capacity Act 2005, Section 2 (1).

¹⁸⁹ United Kingdom (Scotland), Adults with Incapacity (Scotland) Act 2000, Section 87, provides that the definition of ‘mental disorder’, which is found in Section 328 of UK/Mental Health (Care and Treatment) (Scotland) Act 2003 asp. 13, also applies for the purposes of the 2000 Act, and the Mental Health (Northern Ireland) Order 1986, Section 3 (1) on the definition of ‘mental disorder’ and related expressions.

¹⁹⁰ Council of Europe, Committee of Ministers (1999), Explanatory memorandum, para 46: “Measures of protection should not be established for an indefinite duration unless this is necessary or appropriate in the interests of the adult concerned, for instance when the adult who needs the appointment of a representative suffers from senile dementia from which there is no possibility of recovery. Consideration should be given to the institution of periodical reviews of any measure of protection taken [...]”.

¹⁹¹ Belgium, Civil Code, Art. 489.

¹⁹² Cyprus, The Law on Mentally Retarded Persons N. 117/89, Art. 2; Germany, Civil Code, Art. 104, para. 2; Slovakia, Civil Code, Art. 10, paras. 1 and 2; in Romania the terms and the nature of disability are not defined in the legislation; case law, however, has clarified that permanent mental disability must exist for restrictions to be imposed; see Supreme Court (*Tribunalul Suprem, secția civilă*), decision No. 1035/1970.

¹⁸³ Council of Europe, Committee of Ministers (1999), Principle 3, para. 1.

¹⁸⁴ *Ibid.*, Principle 7.

¹⁸⁵ This report does not look at the issue of ‘competence’ and ‘capacity’ of a person; for more information on the discussion on the different approaches to legal capacity see: Dhanda, A. (2007) and Keys, M. (2009).

¹⁸⁶ Italy, Civil Code, Art. 404.

health problem; and is “persistently unable to understand the meaning of or to direct his or her actions”.¹⁹³

In other EU Member States there is no requirement of permanent duration. In the **United Kingdom**, for example, “it does not matter whether the impairment or disturbance is permanent or temporary”.¹⁹⁴ This is the case in **Greece** as well, where an adult may be placed under guardianship if he or she cannot manage his or her own affairs owing to a mental health problem, even if it is of temporary nature.¹⁹⁵

2.2.2. Role of national authorities in guardianship systems

When it comes to civil court judgments, some EU Member States deliver a single combined judgment on the loss of legal capacity and the adoption of a protective measure, while others issue two separate decisions, one on the loss and another on the protective measure. In **Italy**, **Greece** and **Slovenia** the court delivers a single judgment, deciding that the person’s legal capacity is restricted and that he or she will be placed under a protective measure. **Italy** assesses in parallel the question of incapacity and the need to institute a guardianship measure, or to appoint a representative. The same judgment both deprives the person of legal capacity and determines that a guardian will be responsible from then on for the person’s decisions.

In other EU Member States, courts issue two separate judgments. The **Bulgarian** Civil Procedure Code, for example, provides for such a two-stage process. The first stage is a court procedure which limits or removes a person’s legal capacity to exercise rights and accept legal responsibilities. The second is an administrative procedure during which a guardian is appointed for this person.¹⁹⁶ The Bulgarian Family Code stipulates that the mayor in each municipality is the authority responsible for appointing guardians and trustees¹⁹⁷ and for monitoring the guardian’s activities and recommending termination.¹⁹⁸

In some EU Member States that have a two-stage process, the differences relate only to which court has jurisdiction over which issue. This is the case in **Poland**, for example, where the regional court is competent to lead

proceedings and declare restriction of an adult’s legal capacity,¹⁹⁹ while the district court appoints guardians.²⁰⁰

In almost all EU Member States, the civil court is the national authority responsible for restricting or depriving legal capacity and appointing a guardian. In two Member States, **Bulgaria** and **Hungary**, only a court is entitled to limit or restore an adult’s legal capacity, while most other responsibilities, including appointing a guardian, rest with a guardianship authority.

In **Denmark**, the Act on Guardianship grants this decision to the regional state administrations. If the administrative treatment of a case is considered inappropriate, the regional state administrations can opt to forward the case to the Danish courts.

Four Member States have established special courts that deal exclusively with establishing and terminating protection measures and restricting legal capacity. The advantage of special courts is that their judges are likely to be more versed in dealing with legal capacity issues and have a better understanding of the far-reaching consequences of restricting legal capacity. In **Malta**, for example, this role is fulfilled by the Court of Voluntary Jurisdiction for matters of interdiction or incapacitation²⁰¹ or by the Guardianship Board in case of a request for guardianship;²⁰² in **Latvia** by the Orphan Court;²⁰³ in **England** and **Wales** by the Court of Protection;²⁰⁴ and, finally, in **Spain**, by incapacitation courts in several cities (Barcelona, Bilbao, Granada, Madrid, Valencia and Vitoria).

The comparative analysis suggests that the monitoring of the decision’s implementation and follow-up falls within the courts’ competence in approximately half of the EU Member States. In **France**, for example, guardianship judges and the public prosecutor exercise general supervision over guardianships in their jurisdiction.²⁰⁵ Other EU Member States where this is also the case include **Austria**, **Cyprus**, **Latvia**, the **Netherlands** and **Spain**.

Other EU Member States have a dedicated national authority responsible for monitoring the implementation and follow-up of protective measures. **Lithuania** has dedicated municipal or regional institutions, which are responsible for the supervision of designated guardians.²⁰⁶ In **England and Wales**, the Public

¹⁹³ Estonia, General Part of the Civil Code, Art. 8 (2).

¹⁹⁴ United Kingdom (England and Wales), Mental Capacity Act (2005), Art. 2 (2).

¹⁹⁵ Greece, Civil Code, Art. 1666 (1).

¹⁹⁶ Bulgaria, Civil Procedure Code, 1 March 2008, Art. 338.

¹⁹⁷ Bulgaria, Family Code, 1 October 2009, Art. 154.

¹⁹⁸ Bulgaria, Family Code, 1 October 2009, Art. 170.

¹⁹⁹ Poland, Civil Procedure Code, Art. 544, para. 1.

²⁰⁰ Poland, Family and Guardianship Code, Art. 175 in conjunction with Art. 145 (2), and Civil Procedure Code, Art. 16 (1).

²⁰¹ Malta, Civil Code of Organisation and Civil Procedure, Chapter 12 of the Laws of Malta, Art. 520.

²⁰² *Ibid.*, Art. 519A.

²⁰³ Latvia, Civil Procedure Law, Section 268.

²⁰⁴ UK, Mental Capacity Act 2005, c.9, s15 (1).

²⁰⁵ France, Civil Code, Art. 416.

²⁰⁶ Lithuania, Civil Code, Art. 3.241 and 3.278.

Guardian²⁰⁷ is responsible for policing those who act on behalf of persons deprived of legal capacity. **Scotland** also has a Public Guardian authority supported by the Mental Welfare Commission for Scotland, which is required to cooperate with the Public Guardian in protecting the personal welfare of individuals under protective measures.²⁰⁸ **Denmark, Estonia, Hungary and Sweden** have comparable institutions.

2.3. The protective measure: instituting guardianship

Once a person's legal capacity is totally or partially restricted, a protective measure can be instituted. In most EU Member States this will mean the appointment of a guardian. National legal frameworks lay down conditions, however, which must be met before placing a person under guardianship. A test generally consists of two elements: first, medical determination of a mental health problem and, second, assessment of the person's inability to manage his or her own affairs. The test's application differs only slightly from Member State to Member State.

2.3.1. Conditions to be met when placing someone under a protective measure

The principle of necessity introduced by Council of Europe Recommendation Rec(99)4 calls on member states to make sure that "[n]o measure of protection should be established for an incapable adult unless the measure is necessary, taking into account the individual circumstances and the needs of the person concerned [...]"²⁰⁹ A few examples will serve to illustrate the condition established across the 27 EU Member States.

When appointing a personal representative or guardian, the Law on Psychiatric Treatment of **Cyprus** uses the following test, based on the opinion of the responsible psychiatrist and other evidence: "Is the person rendered incompetent/unable to exercise his/her judgment and will? Is the person unable to administer his/her property and manage his/her affairs?"²¹⁰ A guardian will be appointed only if the court, basing its judgment on the psychiatric opinion of the responsible psychiatrist and other evidence, answers these questions positively. In **Denmark**, the Act on Guardianship stipulates three conditions: the person has a mental health problem or intellectual disability; the person is deemed incapable

of managing his or her own affairs; and there is an identified need to establish a guardianship.²¹¹ Likewise, in **France**, a protection procedure is ordered for "any person who cannot provide by himself for his/her own interests because of a medically certified alteration of the mental or physical faculties likely to prevent expression of his/her free will".²¹²

The **Czech** Civil Code, which takes effect on 1 January 2014, amends the provisions on legal capacity and introduces new conditions to be met before instituting restrictions:²¹³

*"[B]efore restricting one's legal capacity, assistance institutes will have to be used in the decision making as well as representation by a household member, or custody without any limitation of the legal capacity to help the person decide in certain more complicated situations. Only in case such institutes are unable to improve the situation of the person with disability, the court can proceed to restrict the person's legal capacity."*²¹⁴

Overall, before instituting a protective measure, the two key principles of necessity and subsidiarity should be taken into account. Moreover, according to the Explanatory Memorandum to Recommendation R(99)4, "any legislation addressing the problem of incapable adults should give a prominent place to these principles".²¹⁵

2.3.2. Persons who can request a protective measure

Instituting a guardianship measure requires serious consideration, because it can have such far-reaching effects. Such a measure should be instituted in a procedurally fair and efficient manner and "there should be adequate procedural safeguards to protect the human rights of the persons concerned and to prevent possible abuses",²¹⁶ according to Recommendation R(99)4. EU Member States differ on one of the key aspects of such a decision: who is authorised to request the placement of a person with intellectual disabilities or mental health problems under a protective measure.

The comparative analysis suggests that EU Member States take three approaches to designating those who may apply for protective measures. A few EU Member States put no limit on who can initiate incapacitation proceedings. In the case of **Ireland**, for example, anyone can present a petition for 'wardship' (guardianship). Normally, a family member is the petitioner and the

207 UK (England and Wales), Mental Capacity Act 2005, Section 9.

208 UK (Scotland), Adults with Incapacity Act (2000), Sections 6 and 7.

209 Council of Europe, Committee of Ministers (1999), Principle 5 (1).

210 Cyprus, Law on Psychiatric Treatment, N. 77(I)/1997, Art. 19.

211 Denmark, Act on Guardianship, No. 1015/2007, Section 5.

212 France, Civil Code, Art. 425.

213 Czech Republic, Civil Code, 1 January 2014, Art. 49–55.

214 UN, CRPD Committee (2011c), p. 20.

215 Council of Europe, Committee of Ministers (1999), Explanatory memorandum, para. 38.

216 Council of Europe, Committee of Ministers (1999), Principle 7 (2).

procedure requires the involvement of a solicitor. When no one is willing to be a petitioner, the Registrar of Wards of Court can initiate the ‘wardship’ procedure.²¹⁷ **Romania** and **Slovakia** take a similar approach. Other legal frameworks allow social care institutions, as well as relatives, to begin the procedure. The **Lithuanian** Civil Code refers specifically to care institutions or a public prosecutor as well as the person’s spouse, parents and adult children.²¹⁸ In **Slovenia**, a centre for social work or a public attorney as well as the spouse, another person who lives with the person, a relative or close family member can initiate the procedure. The affected person can also initiate the procedure if a court finds that he or she is able to understand its meaning and consequences.²¹⁹ A smaller group of Member States restrict the range of persons who can commence the procedure to family members or the public prosecutor. In the **Netherlands**, for instance, the most restrictive form of guardianship can be requested only by a family member or the Public Prosecutor.²²⁰ Similarly, in **Portugal**, the range is limited to the person’s spouse, guardian or carer, a relative who is an heir or the public prosecutor.²²¹ In **France**, this category is broader and includes persons who have “close and stable ties with the person”.²²²

About half of EU Member States explicitly provide in their national legal frameworks for the person concerned to request a restriction of his or her legal capacity. This is the case in **Austria, Denmark, Estonia, Finland, France, Germany, Greece, Italy, Luxembourg, Slovakia, Slovenia, Spain, Sweden** and the **United Kingdom**.

2.3.3. Persons who can be guardians

The guardian appointed to represent, assist and safeguard the person’s well-being should be suitable for the post, according to Council of Europe Recommendation Rec(99)4. Similar wording can be found in national provisions, for example in the **United Kingdom**, where the person appointed should be someone who is “reliable and trustworthy and has an appropriate level of skill and competence to carry out the necessary tasks”.²²³ Many EU Member States stipulate more concrete conditions, such as requiring the person entrusted with the role: to be an adult of over 18 years of age; to have legal capacity; to have no criminal convictions; and to have no conflict of interest.

FRA research shows that in many EU Member States a person’s spouse would be the first choice of guardian.

If this is not possible, then other close relatives, including parents, brothers, sisters, adult children or any other relative, will be considered. If no relative is suitable, national laws offer a variety of subsidiary options. **Austria** and **Belgium**, for example, designate a lawyer, while the **Czech Republic** and **Slovakia** opt for a state official or a state institution, such as a local authority. **Spanish** law names an NGO or any individual who meets the conditions stipulated by law.

An overview of some legal provisions found in the EU-27 exemplifies the different approaches. The **Portuguese** Civil Code expressly entrusts guardianship to the spouse. Failing that, the guardianship would fall to the person’s ascendants, descendants or to a court-appointed guardian.²²⁴ The law in the **Netherlands** explicitly rules out the possibility of a body or institution being a guardian; only individuals can be appointed as guardians.²²⁵

In those EU Member States where a family member cannot be assigned as guardian, a recognised care organisation of a guardianship authority may be permanently vested with the role of guardian. In the **Czech Republic**, the law differentiates between private and public guardians: private guardians are the person’s relatives, who must consent to their appointment and swear an oath before a judge, and public guardians – usually local authorities – are appointed in those cases where there is no private guardian and in this case the consent of the person is not required.²²⁶ In **Spain**, legal entities may perform both guardianships and curatorships provided they are non-profit organisations whose objectives include the protection of incapable persons.²²⁷

Alternatively, in some EU Member States, persons working for guardianship authorities or organisations may be appointed as guardians. Under **German** law, an employee of a care organisation,²²⁸ an employee of an authority responsible for custody matters²²⁹ or a person who works professionally as a custodian may all be appointed as custodians.²³⁰ The court appoints an organisation or an authority and then the body assigns guardian duties to specific individuals.

The majority of EU Member States also take into consideration the will and preference of the person concerned, with provisions designed to follow Principle 9 of Rec(99)4: “[...] the past and present wishes and feelings

217 Ireland, Lunacy Regulation Act 1871, Section 15.

218 Lithuania, Civil Code, Art. 2.10 (4).

219 Slovenia, Non-Litigious Civil Procedure Act, Art. 45.

220 Netherlands, Civil Code, Art. 1:379.

221 Portugal, Civil Code, Art. 141 (1).

222 France, Civil Code, Art. 430.

223 United Kingdom, Mental Capacity Act 2005, Code of Practice, para. 8.32.

224 Portugal, Civil Code, Art. 143.

225 Netherlands, Civil Code, Art. 1:379.

226 Czech Republic, Civil Code, para. 464, when it enters into force on 1 January 2014.

227 Spain, Civil Code, Art. 242.

228 Germany, Civil Code, Art. 1897 (2)1.

229 Germany, Civil Code, Art. 1897 (2)2.

230 Germany, Civil Code, Art. 1897 (6).

of the adult should be ascertained so far as possible, and should be taken into account and given due respect.”²³¹

In **France**, the person placed under guardianship can choose the person or body that will implement the protection measures.²³² The legislative frameworks of **Greece, Hungary, Italy, Lithuania** and the **Netherlands** explicitly mention the need to consult with the person concerned.

The Council of Europe Committee of Ministers Recommendation CM/Rec(2009)11 introduces an anticipatory measure, or ‘advance directive’, thus promoting the “self-determination of capable adults in the event of their future incapacity”.²³³ An ‘advance directive’ enables adults to express their wishes about issues that could arise in the future, such as designating a future guardian. **Austria, Belgium, the Czech Republic, France, Germany, Italy, Spain** and the **United Kingdom** (England and Wales) have such provisions.

Moreover, the **Spanish** legal system allows for ‘auto-guardianship’, under which a person with sufficient legal capacity may, in a notarial public instrument, adopt all provisions with respect to personal issues or assets, including the designation of his or her guardian in case of future loss of legal capacity.²³⁴

2.3.4. Scope and extent of guardian’s authority

Proportionality

The FRA analysis suggests that in many EU Member States the national legal framework stipulates that the principle of proportionality (as enshrined in Principle 6 of Recommendation R(99)4, see Section 1.2.4) should govern the guardian’s scope of power. In **Finland**, for example, the guardian is competent in principle to represent the person deprived of legal capacity in transactions pertaining to the person’s property and financial matters. Following a court order, the guardian may also assume competence to represent the person for personal matters, if he or she cannot understand the significance of his or her decisions and their possible consequences. The guardian is not competent, however, to give consent on behalf of the person represented in all matters. The person represented retains decision-making rights concerning marriage, adoption, acknowledgment of paternity or consent to it, making or revoking a will or representing him- or

herself in other such matters of a personal nature.²³⁵ The statutory frameworks of **Denmark, Germany, Slovakia, Spain, Sweden** and the **United Kingdom** contain similar provisions.

Another group of EU Member States instead use an all-encompassing rather than a ‘tailor-made’ approach to the guardianship. These countries do not limit representation to areas where the person concerned needs assistance. In these countries the guardian must ‘take care’ of the person, manage his or her property and represent him or her in all matters. This is the case, for example, in **Bulgaria**, where the guardian is authorised to make all personal decisions.²³⁶

Free will – ability to make choices under guardianship

The majority of EU Member States take into account the free will of the protected person in their national legislative framework. In **Austria**, for example, each decision of the guardian must be in accordance with the personal will of the individual concerned. If there is a difference in opinion, the judge in the district court must decide on the best solution based on the well-being of the person under guardianship.²³⁷ **Germany** put the system of custodianship in place to better take into account the person’s free will. In their work, custodians must take into account the views of the person, and thereby help maintain his or her identity and accustomed lifestyle. The wishes of the person concerned, including those expressed before the custody order was issued, must also be taken into account.²³⁸

Legislation in several other EU Member States does not oblige the guardian to consider the person’s wishes when taking decisions about his or her life. In **Slovenia**, decisions taken for a person under full guardianship need not consider the adult’s wishes.²³⁹

In cases of partial guardianship, the judge specifies those areas in which the guardian’s consent is needed. For those areas, the effect on the adult is the same as a decision taken by a guardian with full guardianship. In **Poland**, for example, the curator is responsible for assisting the adult under partial guardianship in the management of his or her affairs. Generally, the curator’s consent is necessary in order to approve any legal action the person undertakes.²⁴⁰ There are a few exceptions, such as everyday contracts in minor issues

231 Council of Europe, Committee of Ministers (1999), Principle 9.

232 France, Civil Code, Chapter 2, Section 3.

233 Council of Europe, Committee of Ministers (2009b), Principle 1, para. 2.

234 Spain, Civil Code, Art. 223, 224 and 239.

235 Finland, Guardianship Services Act, No. 442/1999, Chapter 5, Section 29.

236 Bulgaria, Family Code, 1 October 2009, Art. 164, para. 2.

237 Austria, Amendment to the Guardianship Law 2006, Section 281.

238 Palandt, O., et al. (2008); Hellmann, U. (2004).

239 Slovenia, Code of Obligations, Art. 41; Marriage and Family Relations Act, Art. 190–191.

240 Poland, Civil Code, Art. 18 (1), and Art. 19.



of daily life or spending one's own earnings.²⁴¹ Yet the person is, for instance, prohibited from making a will without the consent of the curator.²⁴²

In EU Member States that apply the principle of proportionality, the person placed under protection still retains his or her decision-making powers in areas which are not explicitly covered by guardianship. This is the case in **Greece**, where the person under guardianship can take responsibility for everything that does not specifically fall within the scope of the guardianship measure.²⁴³ In **Sweden**, when a person is under trusteeship, he or she is still allowed to enter into an employment contract, spend his or her salary and control other financial issues, such as insurance policies or savings from retirement plans.²⁴⁴

2.4. Restoration of legal capacity and procedural safeguards

Because a protective measure can impact extensively on a person's life and impose considerable limitations on his or her rights, these measures, whenever possible and appropriate, should be of limited duration, according to Principle 14 of Council of Europe Recommendation R(99)4. More specifically, indefinite legal incapacity should constitute the exception rather than the rule. The CRPD Committee has continuously urged State Parties in its Concluding Observations "to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences".²⁴⁵ The following section will analyse whether EU Member States provide for periodic reviews of protective measures. Furthermore, according to the above principle, "there should be adequate rights of appeal" of the person wishing to challenge the instituted protective measure. National provisions on this aspect are discussed in Section 2.4.2.

2.4.1. Periodic review of the protective measure

Resolution 1642 (2009) of the Parliamentary Assembly of the Council of Europe

Article 7

The Assembly invites member states to guarantee that people with disabilities retain and exercise legal capacity on an equal basis with other members of society by:

[...]

- (3) providing sufficient safeguards against abuse of people under guardianship notably through establishing mechanisms for periodic review of guardian's actions and ensuring that legislation mandates compulsory, regular and meaningful reviews of guardianship, in which the person concerned is fully involved and has adequate legal representation.

Principle 14 (2) of Recommendation R(99)4 calls on Member States to review protective measures "on a change of circumstances and, in particular, on a change in the adult's condition. They should be terminated if the conditions for them are no longer fulfilled." When examining the duration of the protective measure, it is important to see whether EU Member States have provisions instituting 'periodic reviews', understood as mandatory reviews that are automatically initiated after a certain time period. In particular, Principle 14 (1) of Council of Europe Recommendation R(99)4 sets out that member states should consider instituting such periodic reviews.

FRA's research shows that only a few EU Member States set a maximum time limit for reviewing a protective measure. **Germany** sets a time limit of seven years for cancelling or renewing the measure restricting legal capacity.²⁴⁶ Similarly, an **Estonian** court must decide within three years whether to terminate or prolong the guardianship.²⁴⁷ In **Malta**, when a guardian is appointed, the Guardianship Board "shall also order that a hearing for the review (...) be held within specific period, not being longer than two years".²⁴⁸

²⁴¹ Poland, Civil Code, Art. 20 and 21.

²⁴² Poland, Civil Code, Art. 19.

²⁴³ Greece, Civil Code, Art. 1679.

²⁴⁴ Sweden, Code on parenthood and guardianship (SFS: 1949:381), Chapter 11, Art. 8.

²⁴⁵ UN, CRPD Committee (2011a).

²⁴⁶ Germany, Law on Procedure in Family Affairs and in Matters Pertaining to Voluntary Jurisdiction, Art. 294 (3) and 295 (2).

²⁴⁷ Estonia, Code of Civil Procedure, Art. 526 (3).

²⁴⁸ Malta, Civil Code of Organisation and Civil Procedure, Chapter 12 of the Laws of Malta, Art. 519F (4).

French legislation provides for a maximum term of 10 years duration for ‘tutorship’ and ‘curatorship’, renewable once for a five-year period.²⁴⁹ **Austria** and **Latvia** specify similar time limits.

In a few other EU Member States, the judge has discretion whether to appoint a guardian for a specific or an indefinite period of time. This is the case, for example, in **Finland**,²⁵⁰ **Italy** and the **United Kingdom (Scotland)**. Section 58 (4) of the Adults with Incapacity (Scotland) Act 2000 states that “the sheriff [the judge] will normally appoint a guardian for 3 years, but has discretion to vary this, including making the appointment indefinite.”²⁵¹

The comparative analysis shows that in the majority of EU Member States a guardianship measure is in principle instituted for an unlimited period of time and is not subject to periodic review. In **Slovakia**, for instance, there is no maximum time limit for the duration of the protective measure.²⁵² **Bulgaria** is another such example, since the law does not limit the duration of guardianship once it has been established. Other Member States without a statutory maximum duration include **Belgium**, **Cyprus**, the **Czech Republic**, **Greece**, **Ireland**, **Lithuania**, the **Netherlands**, **Poland**, **Portugal**, **Slovenia** and **Spain**.

Some EU Member States whose legislation provides for indefinite guardianship specify that the guardianship should last as long as a guardian is needed. In other words, if the cause behind the restriction of legal capacity no longer exists, then the protective measure should be lifted, as “[m]easures of protection should be reviewed on a change of circumstances and, in particular, on a change in the adult’s condition”.²⁵³ In **Romania**, for example, a person can regain his or her legal capacity only if a court decides that the causes for placing a person under full guardianship no longer exist.²⁵⁴ This is also the case in, for example, **Cyprus**, **Denmark**, **Greece**, **Luxembourg**, the **Netherlands**, **Poland** and **Sweden**.

Although some EU Member States have no mandatory periodic review, a court can still challenge a decision of incapacity, as described in Section 2.4.2.

2.4.2. Challenging the decision on deprivation of legal capacity

Principle 14 (3) of Recommendation R(99)4 calls on Council of Europe member states to ensure that there are adequate rights of appeal. In almost all EU Member States protective measures are, in principle, of unlimited duration, while the majority do not require a mandatory periodic review. Nevertheless, this does not mean that these decisions are never reviewed or that guardianship is instituted forever. In the majority of EU Member States the decision of legal incapacity/protective measure must be appealed before a court will review it. Consequently, EU Member States should ensure that persons with intellectual disabilities or mental health problems have the right to appeal a decision restricting legal capacity and instituting a protective measure.

Deprivation of a person’s legal capacity can sometimes lead to the loss of the person’s right to appear before the court. The majority of EU Member States grant the person the right to appeal this decision, but in a few EU Member States, a person deprived of legal capacity is not guaranteed access to effective remedies. This can make it almost impossible for him or her to restore his or her legal capacity.

All EU Member States allow for an appeal of decisions declaring an adult’s legal incapacity and instituting a protective measure. The question, however, is whether the adult under guardianship can challenge the decision him- or herself. In a few EU Member States the person may not actively participate in the proceedings that could affect his or her legal capacity, in case, for example, the interrogation might harm his or her health or cannot be performed at all. This contradicts the person’s right to be heard in person and is not in compliance with Principle 13 of Recommendation R(99)4 stating that “the person concerned should have the right to be heard in person in any proceedings which could affect his or her legal capacity”. In **Slovakia**, for example, the judgment restricting the person’s legal capacity may not be delivered to the person concerned, if it might cause harm or if he or she cannot understand the purpose of the proceedings.²⁵⁵ The **Czech Republic**, **Estonia** and **Ireland** have similar provisions.

249 France, Civil Code, Art. 441–442. For more information on the degrees of legal capacity restriction in France, see p. 30 (Legal capacity terminology in some EU Member States).

250 Finland, Government Bill HE 146/1998, see Section 4.2 on guardianship administration (*Holhousasioiden hallinto*).

251 United Kingdom, Adults with Incapacity (Scotland) Act 2000, Part 6, Section 58 (4).

252 Slovakia, Civil Code, Art. 10 (3).

253 Council of Europe, Committee of Ministers (1999), Principle 14 (2).

254 Romania, Civil Code, Art. 177.

255 Slovakia, Civil Code, Art. 189.



The person under guardianship can challenge the initial decision instituting the guardianship in several EU Member States. In most cases, the national legislation simply states that those persons eligible to apply for the institution of a protective measure can also challenge it. As discussed in Section 2.3.2, in many EU Member States, the person him- or herself is eligible to request that he or she be assigned a guardian. Similarly, allowing the person under guardianship to challenge the decision him- or herself constitutes an important safeguard for ensuring that his or her wishes are taken into account, respecting his or her autonomy and self-determination.

FRA research shows that the person under guardianship can appeal the decision affecting his or her legal capacity in many EU Member States, for example **Austria, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Italy, Luxembourg, Poland, Spain, Sweden** and the **United Kingdom**. In those Member States, the person under guardianship, as well as other persons 'involved' in the procedure, can also appeal the deprivation of legal capacity. This includes relatives of the person placed under guardianship, the guardian and/or a state authority, such as a public prosecutor.

In other EU Member States, a person under guardianship cannot appeal an incapacity decision because he or she cannot represent him- or herself under the law as a result of that very deprivation he or she wants to appeal. In certain other countries, a person cannot appeal if he or she has been placed under guardianship following two court judgments. In **Bulgaria**, neither adults under partial nor those under full guardianship may apply to have their guardianship lifted as they are deprived of legal capacity. The guardianship authority, or the 'mayor' in the case of Bulgaria, and the guardians alone have this right.²⁵⁶ In the *Stanev v. Bulgaria* case, the ECtHR concluded that this incapacity violates Article 6 (1) of the ECHR on the right to a fair hearing, since the complainant was denied access to a court to seek restoration of his legal capacity (see Section 1.2.2).²⁵⁷

²⁵⁶ Bulgaria, Civil Procedure Code, 1 March 2008, Art. 340.

²⁵⁷ ECtHR, *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012, para. 243.

3

Personal accounts – evidence from fieldwork research



To help illuminate the complex issue of legal capacity, FRA spoke to persons with mental health problems and persons with intellectual disabilities to learn about their experiences of guardianship and restricted decision-making. Their stories, captured in the findings of FRA's in-depth qualitative fieldwork research,²⁵⁸ not only give voice to those who are seldom heard but help to contextualise the legal framework, offering an inside view of how the legal system affects the lives of persons with disabilities which can inform the on-going reform of legal capacity legislation across EU Member States.

The fieldwork was carried out using semi-structured interviews and focus groups with 115 persons with mental health problems and 105 persons with intellectual disabilities in nine EU Member States (Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden and the United Kingdom) between November 2010 and July 2011. Notably, the sample did not include persons living in large institutions or persons under guardianship whose guardians did not consent to them being interviewed. Additional focus group interviews were conducted in each of the nine EU Member States with selected stakeholders with relevant expertise relating to persons with mental health problems or with intellectual disabilities. The organisations represented varied between EU Member States and, wherever possible, included a representative of a mental health service user-led organisation or group, self-advocacy organisations, representatives of government

departments, representatives of ombudsman offices or national human rights institutions and representatives of relevant professional bodies, such as psychiatrists and social workers.

The qualitative research generated a wealth of information about a broad range of issues related to the autonomy and inclusion of persons with disabilities. These are presented in the report *Choice and control: the right to independent living – Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States*. The nature of the research required the selection of a small sample of individuals, which was not intended to be representative of the total population of persons with mental health problems or persons with intellectual disabilities. Moreover, as persons under guardianship were interviewed only with the consent of their guardian, some individuals whose legal capacity had been restricted were excluded from the research.

While the interviews and focus groups with persons with mental health problems were conducted separately from those with persons with intellectual disabilities, their experiences are analysed together in this report. This in no way minimises the clear distinctions between mental health problems and intellectual disabilities. Instead, it reflects how the responses of persons with mental health problems and persons with intellectual disabilities highlighted commonalities in their experiences of legal incapacity, informal restrictions on their ability to make decisions and supported decision-making. In this report, individual responses are clearly identified as those of a person with mental health problems or a person with intellectual disabilities, reflecting the personal nature of the description.²⁵⁹

²⁵⁸ Country researchers in each of the nine EU Member States covered by the project carried out the fieldwork research for FRA, namely: Slavka Kukova (Bulgaria), Dominique Velche (France), Petra Gromann (Germany), Maria Mousmouti (Greece), Tamas Gyulavári (Hungary), Ieva Leimane-Veldmeijere (Latvia), Georgiana Pascu (Romania), Rafael Lindqvist (Sweden) and Sarah Woodin (United Kingdom). For more detailed information on the methodology and research consortium for the FRA project 'The fundamental rights of persons with mental health problems and persons with intellectual disabilities', including an analysis of methodological challenges and limitations, see: FRA (2012b).

²⁵⁹ Persons with mental health problems and persons with intellectual disabilities will be referred to in the following sections as 'research participants', 'interviewees' and 'respondents' interchangeably to avoid repetition.

3.1. Formal restrictions of legal capacity

Many of the FRA research participants had at some point lost their legal capacity – either totally or in part – as a result of formal legal measures. Reflecting the wide variety of laws in place, respondents described experiences of a range of different types of protective measures and with guardians who exercised varying degrees of decision-making powers. This section does not parallel the report’s earlier comparative legal analysis because the respondents did not describe their experiences of guardianship in this way. Nonetheless, the participants addressed many of the key legal issues presented, namely the process of being deprived of legal capacity, being able to choose one’s guardian, awareness of losing one’s legal capacity and the role of a guardian, the scope of a guardian’s decision-making power, challenging a decision to remove one’s legal capacity and regaining legal capacity.

Around half of the research respondents with intellectual disabilities had been wholly or partially deprived of their legal capacity and placed under a form of guardianship at some point in their lives, including a majority of respondents in Germany, Greece and Hungary. Half of the participants with intellectual disabilities in France had a curator (*curateur*) and half in Sweden had a mentor (*god man*); curators and mentors can take legally binding decisions only with the agreement or consent of the person concerned, as described in Section 2.1.1 of this report.

Far fewer of the interviewees with mental health problems had experienced formal restrictions of their legal capacity. A small number of participants from Bulgaria, Germany and Hungary were under a form of guardianship at the time of the interview, while one participant in Latvia was in the midst of proceedings to deprive him of his legal capacity. A number of other participants had been under guardianship in the past but had since regained legal capacity. In addition, a third of respondents in France were under curatorship (*curateur*) and a small number of respondents in Sweden had a mentor (*god man*).

3.1.1. Losing legal capacity

The procedure for depriving a person of their legal capacity, as well as the criteria prescribed in national legislation, are similar across EU Member States, as described in Section 2.2. In almost all EU Member States, before incapacity measures can be instituted the presence of a particular medical condition must be coupled with an individual’s ‘inability’ or ‘loss of capacity’ to manage their affairs. Respondents with mental health problems and respondents with intellectual disabilities

explained why they felt restrictions on their legal capacity had been initiated; their experiences of the legal process; and whether they had the opportunity to choose their guardian.

Initiating the restriction of legal capacity

A small number of participants reflected on why a process to deprive them of their legal capacity had been initiated. Several interviewees with mental health problems spoke of guardianship proceedings triggered by disputes with family members:

“We had quarrels with my mother before the hospital. She made my Roma girlfriend have an abortion in the village where we lived with her. [...] I wanted the child but she told me I am not ready to have a child. [...] I was angry because I did not know. [...] My mother brought my girlfriend to the place and paid for the abortion. [...] So they punished me with compulsory treatment [...] while I was in the hospital she became my guardian.”

(Man with mental health problems, 41, Bulgaria)

Other respondents described being deprived of legal capacity in order to protect their financial and property assets. This was particularly mentioned in relation to inheritance and compensation claims, as in the case of a man with intellectual disabilities in France who sought damages following sexual abuse:

“My lawyer said ‘We can claim for damages’. I said ‘yes’. She claimed 15,000 francs [€2,300]. But the court did not want to give out the sum as long as I wasn’t under protection. Because my mother was always drunk, they feared that she would claim it, and I wouldn’t know how to say ‘No’. It would disappear too quickly.”

(Man with intellectual disabilities, 31, France)

Similarly, respondents with intellectual disabilities or mental health problems from France and Sweden said the reason they had a curator or mentor stemmed from their difficulties in dealing with household bills when living alone. A respondent with mental health problems in France requested a curator to assist with managing her income, as her depression meant she found it difficult to cope with paying taxes and utility bills, and she felt that curatorship could reduce the risk of losing her apartment.

Assessment of mental capacity

A number of respondents, predominantly those with mental health problems, reflected on the process of having their mental capacity assessed. Two men recalled their expert assessments:



"A young psychologist came up to me in the hospital and asked me to do something. She brought a sheet of paper and a pencil and asked me to draw a picture of a farmhouse and a man and a woman on a rainy day on one side of the sheet. On the other side she asked me to draw an animal that has never existed [...]. So I drew a timber house and a man holding an umbrella. On the other side, well, I was supposed to draw an animal that does not exist. So I started to draw something with a cow's head, a woman's lips, horns, feathers [...], seven talons, and whatever else I could think of. And then she took it and looked at it. And I said, 'What do you think?' [...] 'Not bad' – she said, then she left, [she] did not say another word".

(Man with mental health problems, 68, Latvia)

"I did about half of it before realising that the whole thing was a complete farce. The questions are such that no matter how you answer they make you seem mentally ill. [...] Do you want to be a painter? [...] Do you think there is a higher power? And another interesting one – do you want to draw pictures of children? If you were a painter, would you like to draw pictures of children? You can only agree or disagree. So I have to assume that I would like to be a painter. If I answer that I would like to draw children, then I am a paedophile, whereas if I do not want to I am a child murderer, because I do not like children".

(Man with mental health problems, 23, Latvia)

A respondent with intellectual disabilities described a visit by assessors to his home:

"They came here and had a look at the house and how many t-shirts I have and trousers, like the ones I'm wearing now. And they also came to ask me what I liked most."

(Man with intellectual disabilities, 24, Hungary)

Respondents in Bulgaria, Hungary and Latvia reported being unaware of what was happening at the time the restriction of their legal capacity was being considered. One woman in Hungary described how a psychiatric hospital initiated proceedings without prior discussion and against her will. When she complied with a request to go to hospital for an unscheduled visit:

"I will never forget it. [T]hey did not say anything about the reason for the visit [...] all they asked was how I was [...]. I told them I was well and thanked them. The next thing I knew was that my judgment was limited and therefore I needed to be placed under guardianship."

(Woman with mental health problems, 36, Hungary)

Two other respondents recalled their experiences of the court hearing which determined whether they retained or lost their legal capacity. One man said he was sedated at the hospital before being taken to the court:

"I was sleepy and they did not try to explain anything to me."

(Man with mental health problems, 41, Bulgaria)

A man in Latvia was not invited to the court hearing after the experts on the committee assessing his mental capacity judged that his health did not permit him to attend, a decision which angered him:

"They did it all behind my back even though legally they were not allowed to."

(Man with mental health problems, 69, Latvia)

The appointment of a guardian

Interviewees also reported varied experiences of being allocated or choosing a guardian following the loss of their legal capacity. In a majority of EU Member States, national laws contain provisions indicating that the will and preference of the individual under a protective measure should be taken into account when selecting a guardian. Of the countries covered by the fieldwork research, national legislation in France, Greece and Hungary specifically mentions the need for the individual's choice to be considered.

Participants in France, Germany and Sweden spoke positively about the process of choosing a guardian and their involvement in it:

"Someone from the court came [...] and then I chose her (the guardian) myself [...] I do think it works well."

(Woman with mental health problems, 50, Germany)

In Sweden, one man with mental health problems explained that he had requested a mentor and been able to choose one he liked, while a woman with intellectual disabilities recalled that her caseworker from social services had suggested she meet her mentor first. Once she met and liked the person, she opted to make this person her mentor. A man with mental health problems in France described how he had been able to change his curator to an outside professional from a family member to ease the strain that the curatorship placed on family relations.

Other participants recalled negative experiences and said that a guardian had been appointed for them without consultation. Respondents with intellectual disabilities in Sweden said other people decided that they should have a mentor and who this person should be. One woman with mental health problems in France reported that an organisation specialising in guardianship chose her curator. Another interviewee from Hungary, who had recently lost her legal capacity, was waiting to find out who the court would appoint as guardian:

"I don't know yet but I will receive a letter soon. It is still in progress as it only happened last month. [...] It will be an officially appointed representative but I don't know who it will be. I will receive a letter with the information."

(Woman with mental health problems, 36, Hungary)

Few participants commented on legal safeguards regarding guardianship, although one respondent called for more rigorous assessments:

“Don’t just give everyone a guardian, check more carefully.”

(Respondent with intellectual disabilities, Germany)

Stakeholders in the field of mental health in Hungary suggested that the legal capacity procedure should be reviewed to provide additional safeguards. They recommended requiring the involvement of others, such as social workers, to make the process less dependent on psychiatrists. They also highlighted that support with decision-making may be needed only short term during periods of crisis, and that the guardianship system should be sufficiently flexible to allow for this.

3.1.2. Experiences of guardianship

Many of the interviewees who had had their legal capacity restricted or removed talked about their experiences of guardianship and the different areas in which guardians were empowered to make legally recognised decisions on their behalf. Respondents spoke both about their general experiences of guardianship and about specific elements, including: their awareness of the role of a guardian; involuntary placement and treatment; and key areas of life where guardians exercised decision-making power, such as control over finances, where to live, access to welfare services and support in administrative tasks. Many of these experiences related to specific rights as set out in the CRPD, including: Article 19 on living independently and being included in the community; Article 22 on respect for privacy; Article 23 on respect for home and the family; and Article 25 on health; as well as to Recommendation R(99)4, principles of proportionality, necessity and maximum preservation of capacity.

A number of respondents, particularly those with intellectual disabilities, spoke negatively about guardianship overall and the restriction on their ability to make decisions. In Sweden persons with intellectual disabilities said that mentors and trustees decided too much at the expense of their autonomy and self-determination. One woman living in a residential home in the United Kingdom described how severely curtailed were her opportunities for making even small decisions such as what time to get up and what to eat:

“My mum is my guardian and I can’t say ‘no’ to her. If she wants me she can phone up the house. And the house phones her. Everything is controlled by her. And I can’t breathe. Because she’s there – in my face. In this. In that. And you know she’s everywhere. [...] I know she’s my mum but I’ve tried to move away from her slowly but it’s not working.”

(Woman with intellectual disabilities, 27, United Kingdom)

Another respondent with mental health problems outlined her reluctance to be placed under guardianship and concern about the impact it could have on her autonomy:

“A guardian: that would be the worst thing I could imagine.”

(Woman with mental health problems, 52, Germany)

On the other hand, other respondents expressed positive overall opinions of guardianship and the decision-making support that guardians could provide. Most participants in the focus group for persons with intellectual disabilities in Hungary, for example, welcomed the opportunity to discuss decisions with their guardians:

Interviewer: “And what do you think about guardianship?”

Participants: “It’s good.”

Interviewer: “And why is it good for you to have a guardian?”

Participant: “We can discuss everything together, and then we can achieve what we want with a common agreement.”

Participant: “We can talk about things [...]. If one does not understand anything, he can discuss it with the guardian, and the situation is solved. [...] It was also good for me that my guardian looked after me when I was ill.”

(Focus group with respondents with intellectual disabilities, Hungary)

Most respondents with intellectual disabilities in France reported that their guardians and curators offered real support in their lives, as they assisted in resolving budgetary and administrative problems, as well as helped look for a good place to live. Similarly, two respondents with mental health problems in Sweden reported positive experiences with their mentors. In one case the mentor assisted the respondent in navigating the welfare system, while in the other the mentor assisted the individual with finances.

One recurrent theme of experiences of guardianship was the importance of a positive relationship between persons with disabilities and their guardians. Two respondents in Germany, for example, felt that the guardianship system could be improved by having guardians spend more time supporting decision-making and building up strong personal relationships with the person deprived of legal capacity:

“[There should be] not so much written communication, more personal contact, getting into direct conversation.”

(Respondent with intellectual disabilities, Germany)

“In general I think the instrument of guardianship is very good, just that the guardians have far too little time for [people under guardianship] and that leads to a lot of difficulties.”

(Respondent with mental health problems, Germany)

When tensions emerged, interviewees indicated that their ability to influence their guardians' decisions and the support they were given to take decisions for themselves were markedly reduced.

Awareness of the role of guardian

Interviews with respondents from both groups of persons with disabilities indicated that they sometimes lacked awareness of the guardian's role and the scope of his or her decision-making power. Among participants with mental health problems, respondents in Bulgaria, Hungary, Latvia and Romania were sometimes unaware of the implications of being placed under guardianship and even about whether or not this had happened to them:

Interviewer: "Do you know the procedure to obtain guardianship? Do you know the effects of guardianship over your life?"

Respondent: "No, I don't have any information about this."

(Woman with mental health problems, 42, Romania)

Similarly, several respondents with intellectual disabilities had either very little or only a vague understanding of what guardianship was and what guardians could do. Many interviewees in Hungary, for example, thought that guardianship was linked to receiving social benefits:

"My mother is my guardian. [...] It means that she supports me financially. [...] It means that the guardianship includes my mother and whoever was at home. So this means that I receive some family allowance and this is why I was placed under guardianship."

(Man with intellectual disabilities, 24, Hungary)

The majority of respondents with intellectual disabilities in Romania could not describe the process through which guardians take decisions for persons deprived of legal capacity and whether they had to follow certain rules. The only exceptions were two participants involved in self-advocacy, who could describe the process in detail:

"Well, first of all I consult with my mother when I take a decision, I take the decision by myself, but I always ask my mother if she agrees with the choice I've made."

(Woman with mental health problems, 37, Romania)

Other respondents, in contrast, were very clear about the limits guardianship placed on their ability to take decisions:

"I am under comprehensive guardianship. [...] Because of this I cannot vote and we cannot get married either. I am not the only one with these problems, there are many of us. I cannot sign an employment contract; I cannot work so I have many such disadvantages."

(Man with intellectual disabilities, 53, Hungary)

Similarly, a number of participants with intellectual disabilities in Romania distinguished between everyday decisions and more important decisions concerning their treatment and the use of their disability allowance: most acknowledged that they did not make the latter type of decisions:

"I get a small disability allowance. [...] My mother takes this money."

(Man with intellectual disabilities, 21, Romania)

"At the beginning I said [the pills] didn't help me, I lied so I wouldn't have to take them [...] because they tasted bad. [...] But I kept taking them, because my sister told me to take the pills."

(Woman with intellectual disabilities, 23, Romania)

Involuntary placement and involuntary treatment

Only respondents with mental health problems discussed their experiences of involuntary placement or involuntary treatment. FRA presents most of these experiences in the report *Involuntary placement and involuntary treatment of persons with mental health problems*, which provides evidence of the lived experience of persons with mental health problems related to involuntary placement, involuntary treatment, and seclusion and restraint.²⁶⁰

The loss of legal capacity and placement under guardianship can be closely tied to compulsory measures. As none of the FRA research respondents lived in long-stay institutions at the time of the interviews, all of the events relating to such institutions occurred in the past and do not necessarily reflect the current situation.

For a number of participants in Bulgaria and Latvia, the imposition of guardianship took away their choice about placement in a psychiatric hospital and receiving treatment. Stakeholders working in the field of disability in Sweden emphasised that both legal capacity and access to justice are crucial in the context of involuntary placement or treatment.

Interviewees in Latvia explained one link between legal capacity and compulsory measures: relatives acting on the basis of a psychiatrist's recommendation initiate legal proceedings to have a person's legal capacity revoked so that the person can be admitted to a psychiatric hospital or treated involuntarily:

"[My mother] had already said that, together with [the doctor], they would have me legally incapacitated if I did not take my medication. [...] X is a doctor my mother talked to all the time and who I went to the first two times and who arranged this disability status for me."

(Man with mental health problems, 23, Latvia)

²⁶⁰ FRA (2012a).

Once legal capacity is removed, the guardian, rather than the person concerned, gives consent for placement and treatment. A hospital doctor told a man in Latvia, for example, that his legal capacity had been revoked and that he was being transferred to a long-term psychiatric hospital.

Several participants said that they felt restricted in their decision-making because they were afraid compulsory measures would be imposed if they were judged to be behaving unwisely. One woman in the United Kingdom described how she agreed to voluntary admission to hospital to avoid what she believed would otherwise be an involuntary placement.

Control over personal finances

Loss of control over personal finances emerged as a major theme for both interviewees with mental health problems and interviewees with intellectual disabilities who had experience of legal incapacity. This may reflect how, in several EU Member States, guardians can be appointed specifically to take decisions regarding an individual's finances. This is the case, for example, in France, where a curator assists with the management of a person's income but cannot take decisions outside that sphere.²⁶¹

Two respondents with intellectual disabilities reflected on the impact of guardianship over their financial activities and the different roles guardians can play in their financial affairs:

"Well, I would have less freedom concerning my budget, because I heard some people saying 'Yes, if you have a curator, he will give you this and this every week, you will receive only €80 for yourself and your shopping. You will have less freedom for your budget'. On the one hand it's OK, but on the other hand I don't fancy it at all."

(Man with intellectual disabilities, 20, France)

Conversely, one man in Sweden thought that his trustee, who could take decisions without his consent, was better than a mentor, who needed that consent before taking a legally binding decision:

"Because I can't go out and buy that car or sign up for a contract with a phone provider because the trustee has the last word. I trust him and he trusts me. I have always wanted it that way, because I can't handle real money. I have had a trustee for over 10 years, ever since I got the [disability] pension."

(Man with intellectual disabilities, 31, Sweden)

Respondents reported different ways in which the loss of legal capacity affected their ability to control their personal finances. Some spoke about the relationship between guardianship and inheritance. One woman with mental health problems in France, for example, recalled how on one occasion her guardian acted on her behalf against her will: she did not want to sign the documents to sell a house that she had inherited and the guardian signed in her place. In Romania, stakeholders in the focus group on mental health explained that parents sometimes used guardianship to protect their children with mental health problems from possible abuses by others, such as being pressured to sign documents relating to inheritance.

Other participants focused on control over daily expenses. Some interviewees said that their guardians gave them the money they required:

"[The guardian is] a bit stubborn, but he does give me, when I need money, I mean in my account, when I need something, he does give it to me. He plans for me, just like he plans for himself."

(Man with mental health problems, 51, Germany)

"This means that if I really like something then we buy it."

(Man with intellectual disabilities, 24, Hungary)

Similarly, the two participants with mental health problems in Sweden who had mentors found no unwelcome restrictions on their choice and control over day-to-day living, saying that the arrangement provided useful support with managing finances and applying for additional funds.

Others, in contrast, reported more negative experiences of guardians exercising control over their finances. One woman recalled, for example, how her mother had tried to revoke her parental rights and control her child support benefit and pension:

"She even wanted to take away my parental rights. [...] While I was at home, she always tried to control my money and asked me to sign a power of attorney, and she received my money and did not give me any of it [...] and she bought my sister a car with the money I received. For more than a year she was receiving money. [...] I did not know why my signature was needed, and I just signed. [...] And when I was still getting the money myself, she would come with me to the store to see what I bought."

(Woman with mental health problems, 27, Latvia)

A number of participants expressed frustration that their guardians did not always give them money when they asked for it. One man with mental health problems in France was unhappy that his curator restricted his spending.

Respondents with intellectual disabilities reported that they often consulted closely with their guardians

²⁶¹ For more information regarding the different types of guardianship and supported decision-making available in some EU Member States, see the boxes in Sections 2.1.1 and 3.3.

– frequently family members – regarding how to spend even small amounts of money. While illustrating the support families can provide, this may also indicate how the distinction between family member and guardian can become blurred:

Interviewer: “What do you normally buy with your pocket money?”

Man: “Well, it depends. If I really fancy something then I ask my grandma and she will tell me whether I can buy it or not.”

Interviewer: “Do you always ask her?”

Man: “Yes, I do.”

Interviewer: “Do you always want to ask her or is this something she asked you to do?”

Man: “She is my guardian so therefore I always have to ask her about everything. [...] I always discuss everything with her – just to be on the safe side.”

(Man with intellectual disabilities, 37, Hungary)

Choice about where to live and daily activities

Interviewees said guardians also exercised decision-making power over where and with whom they lived. Article 19 (a) of the CRPD stipulates that persons with disabilities should have the opportunity to choose their place of residence on an equal basis with others and not be obliged to live in a particular living arrangement.

Some welcomed assistance in choosing where to live:

“My curator helped me to choose the place I am living now. I am pleased but sometimes I feel lonely.”

(Man with mental health problems, 50, Greece)

Most, however, did not like guardians taking decisions over where they should live. This often reflected tensions between persons with disabilities and family members who had been appointed guardians. One woman living in a protected home in Bulgaria wanted to live in her grandmother’s house, but her uncle, who is on her guardianship council, disagreed:

“He told me that he is afraid I would not be able to live alone in the house as it is not safe. He thinks there is a chance that I might be attacked by criminals as the house is located in the suburbs of a village.”

(Woman with intellectual disabilities, 44, Bulgaria)

Another respondent reflected on how a lack of independent support to make decisions could leave persons with mental health problems open to what she felt was ‘manipulation’ by family members:

“But there are some people who are manipulative, for example a friend of mine lost her property that way. She was pushed over the edge by people telling her to go to different places all the time. She was physically and emotionally exhausted. Afterwards all her relatives got together and told her “Now sign these papers”. And she signed. Now she lives in a social care institution.”

(Woman with mental health problems, 25, Latvia)

Assistance in accessing or managing welfare payments, healthcare agencies and other administrative tasks emerged as an important theme among interviewees, particularly in Sweden. In most cases they described their experiences in positive terms:

“It was a good time actually and he was a good guardian [...] he did my paperwork with me, usually we just had meetings or we went out for a quick coffee.”

(Respondent with a mental health problems, Germany)

A man with mental health problems in Sweden explained that he had a mentor because he needed somebody to assist him when dealing with various welfare agencies. Communicating with social workers drained his energy and left him feeling exhausted:

“It’s really humiliating to meet the social worker and tell your story once again, to disclose your life situation, even though I know that they are bound by confidentiality.”

(Man with mental health problems, 31, Sweden)

In contrast, a participant in Sweden with intellectual disabilities recalled how his first mentor rarely visited him. When she brought him money, she stayed in her car and expected him to come down from his apartment to pick it up. He felt she did not take her role seriously, particularly when she neglected to apply for sickness benefits from the social security office. Although the mentor allegedly did not acknowledge her role in failing to apply for benefits, the interviewee complained to the Chief Guardian and now has another mentor.

3.1.3. Challenging guardianship and regaining legal capacity

International human rights standards, as well as national laws in most EU Member States, contain a number of provisions regarding the review and appeal of a legal incapacity decision, as discussed in Chapters 1 and 2. Very few interviewees, however, had sought to challenge the decision depriving them of legal capacity or to change their guardian. Instead, respondents – predominantly those with mental health problems but also a few interviewees with intellectual disabilities – highlighted some of the factors that discouraged them from appealing incapacity decisions. Of those who had challenged the guardianship measure, several had succeeded in regaining their legal capacity or in changing their guardian.

Respondents said that previous experience with the legal incapacity process was a major factor keeping them from pursuing an appeal, as it could be lengthy and frustrating. They also focused on the emotional stress and strain associated with challenging the loss of legal capacity:

"The judge said that if I appealed there would be a review inspection followed by several court hearings. You cannot imagine how many times I would need to go to the court. Sometimes this person does not turn up at the court, sometimes another so they keep adjourning the hearings. This presents a serious psychological burden for me: as soon as I see the court I become very anxious. What am I doing there? This is terrible. There are many other defendants and other people sitting there looking at me. I wonder what they think I am doing there."

(Woman with mental health problems, 36, Hungary)

Others identified practical obstacles to challenging guardianship. In one case, a woman with mental health problems in Bulgaria explained that, after her mother developed Alzheimer's disease, her uncle and aunt began taking decisions about the family property. The respondent was unable to challenge these decisions as her mother had placed her under guardianship. When she later tried to lift her guardianship, the lawyers she consulted told her that she did not have the right to initiate such proceedings because of her legal incapacity.

Participants in both the mental health and the intellectual disability focus groups in Hungary underlined the difficulties of making complaints within the framework of guardianship regimes. They spoke of situations in which the guardian represented the structure which was being criticised, such as a local government, and was not an independent expert. This was particularly problematic for persons with disabilities living in institutions, who are mostly under guardianship and therefore do not have legal standing within the institutional framework. To make a complaint, they need their officially appointed guardian's support. Guardians are often local government employees, making it difficult for them to support complaints, as the local government may manage the institution.

Stakeholders taking part in the focus groups in Romania said that a lack of awareness or information about how to challenge legal incapacity was another major reason why persons with disabilities did not request the removal of guardianship. This was reflected in the responses of one interviewee with intellectual disabilities when asked about her understanding of making a complaint:

Interviewer: "Do you understand now what a complaint is?"

Participant: "Yes."

Interviewer: "Did you ever file a complaint?"

Participant: "No, never."

Interviewer: "Did you ever learn how to make a complaint? Do you know where to make one?"

Participant: "No."

Interviewer: "Do you think it would be good to learn how to make complaints?"

Participant: "Yes, it would be good."

Interviewer: "But would you make any?"

Participant: No. [...] I don't have the courage."

(Woman with intellectual disabilities, 25, Romania)

Respondents in Latvia, Romania and Sweden described cases of persons with disabilities regaining their legal capacity or changing their guardians. Stakeholders in Romania mentioned two examples of persons with mental health problems who succeeded in having their guardianship lifted. A female participant with intellectual disabilities in Sweden managed to have her brother-in-law, who had been her mentor for 20 years but whom she described as 'greedy', replaced by a mentor her social worker suggested.

Respondents who had sought to regain their legal capacity highlighted the importance of support in challenging guardianship decisions. One man succeeded in having his legal capacity restored after 10 years with the assistance of hospital staff and an NGO which arranged the services of an attorney free of charge. He recalled how, at the start of the process, neither he nor the staff at the institution knew how to proceed, and things only started moving forward when the attorney became involved:

"[The attorney] came to the hospital and we had a conversation. Yes. We talked about my activities, the newspaper articles I had written, and about my public activities. And about a month later he requested that my guardian give him a power of attorney to handle all matters regarding my case."

(Man with mental health problems, 68, Latvia)

The court commissioned an outpatient expert psychiatric assessment to determine whether or not to restore his legal capacity. The assessment was positive and the court ruled that his legal capacity should be renewed, allowing him to leave the institution and move into a group apartment.



3.2. Informal restrictions on decision-making

In addition to their experiences of formal legal incapacity procedures and guardianship regimes, respondents from all EU Member States included in the FRA research spoke about informal restrictions on decision-making about their lives. These experiences often occurred independently of any formal guardianship regime or legal process, and many of the respondents whose experiences are presented here retained full legal capacity. Their descriptions highlight how the opportunities for persons with disabilities to exercise control over their lives can be constrained irrespective of their legal status.

Interviewees mostly talked about experiences of having their decision-making power curtailed in community life, although some referred to such informal restrictions in institutions. In many cases, these restrictions reflected an assumption that people with disabilities lacked the capacity to exercise rights responsibly and to make choices for themselves. Respondents described how some professionals and parents share paternalistic attitudes and practices that increased dependency and impeded the ability of persons with disabilities to take their own decisions, as presented in more depth in the FRA report *Choice and control: the right to independent living*.²⁶² Participants at the conference where the report was launched in June 2012 reflected on what they felt was a lack of acknowledgement that people with disabilities have a ‘right to take risks’ and to learn from their mistakes on an equal basis with others.²⁶³

During the FRA fieldwork research, respondents spoke of a range of factors which restricted their ability to take decisions, often linked to low expectations of persons with disabilities. Stakeholders at the focus group on intellectual disability in Hungary explained how people with disabilities are not trained to build up the skills that would enable them to recognise situations in which they could take decisions, to consider alternatives to a course of action or to envisage the consequences of a decision.

Some respondents with mental health problems also described their fear of taking decisions, which might reflect a lack of support:

“I think it would be better if somebody told me their opinion.”

(Man with mental health problems, 40, Hungary)

Interviewer: “Do you feel that the stakes of your decisions are huge?”

Participant: “Yes, that’s right, I am afraid of taking decisions.”

(Man with mental health problems, Hungary, 52)

In addition, a number of respondents indicated that they did not wish to take decisions:

“I go wherever my parents want; I do not want to choose.”

(Man with intellectual disabilities, Greece)

Most interviewees with intellectual disabilities in Romania could not describe how decisions were taken on their behalf; neither the staff at their day centres nor their family had explained to them why certain decisions had to be taken or what they meant. Similarly, respondents with intellectual disabilities in the United Kingdom reported a lack of information about opportunities to take decisions and said that, in practice, decisions were often limited to whether or not to take part in things other people organised.

Although in many cases families were an invaluable source of support for both people with intellectual disabilities and people with mental health problems, some respondents said that their families restricted their choices, especially when they depended on them financially. Such ‘informal coercion’ related to issues of property and inheritance, decisions about whether to have children, as well as treatment and medication. Interviewees with mental health problems in Latvia and Romania who retained their legal capacity recalled, for example, instances when their parents had tried to restrict their personal freedom, while three respondents in France said that, although they did not have formal guardians, family members took decisions for them. Respondents with intellectual disabilities in Romania highlighted that it was difficult to challenge family pressure because parents often acted as the contact point with medical professionals:

“Unfortunately [the doctor] doesn’t discuss [my treatment] with me, but with my mother.”

(Man with intellectual disabilities, 30, Romania)

Many of the respondents with intellectual disabilities who lived with their families did not view the question of guardianship and of others taking decisions for them as a major issue. They considered it ‘normal’ for close relatives to take responsibility for daily tasks and decision-making:

“Dad does all that.”

(Respondent with intellectual disabilities, Germany)

“I’d talk to my mother about it first.”

(Respondent with intellectual disabilities, Germany)

²⁶² FRA (2012b).

²⁶³ For more information, see:

<http://fra.europa.eu/en/event/2012/conference-autonomy-and-inclusion-people-disabilities>.

As they felt well integrated in their family and experienced the influence of the family as positive, these interviewees generally did not raise the issue of dependency or potential conflicts of interest.

3.2.1. Restrictions on decision-making in institutions

Respondents who had previously spent time in institutions recalled how institutional cultures or staff curbed their ability to take decisions:

“First you have to get well, then you can take your own decisions when you are at home.”

(Man with mental health problems, Latvia)

Participants with intellectual disabilities in Bulgaria who had previously lived in large institutions spoke very positively about their move to protected group homes where they had more opportunities to take decisions. They explained how in these protected group homes they were able to decide what clothes to wear and what to watch on television, although they were limited in their ability to choose when to leave the home or invite friends to visit, whom to meet and how to express their views and wishes:

“We choose what programme to watch, we like several movies and programmes. We all have our own clothes and the social workers come with us when we need to buy clothes and other things [...]. They do not allow us to go alone in the city as they are responsible for us and they are afraid something bad might happen to us.”

(Woman with intellectual disabilities, 44, Bulgaria)

“It is better to meet people outside the protected home as they would ask me who they are. [...] I am supposed to be [at the protected home] at around 7 p.m. as otherwise they will not give me my dinner.”

(Man with intellectual disabilities, 21, Bulgaria)

In Latvia and Romania, two participants who had spent many years in psychiatric hospitals felt that in general the situation had improved:

“Things have changed in the last 10 years, the nurses invite you to come into the procedure room and sit down. It means a lot if you can sit down and have a discussion.”

(Respondent with mental health problems, Latvia)

“To receive and make phone calls, for periods of time this was conditioned and restricted very much, but most recently phone calls were available.”

(Man with mental health problems, 44, Romania)

3.2.2. Restrictions on decision-making in the community

Many of the interviewees talked about informal restrictions on their ability to take decisions while living in the community, particularly in relation to decisions about where to live and daily activities. Participants with mental health problems also discussed how their freedom to take decisions about marriage, relationships, having children, healthcare and psychiatric treatment was curtailed. In cases where family members were also legal guardians, the distinction between formal and informal restrictions on legal capacity was often blurred.

Choices about where to live and daily activities

Participants discussed a number of informal restrictions on their right to decide where to live and what to do on a daily basis. These constraints largely stemmed from their reliance on their families for financial support and accommodation. Both people with mental health problems and people with intellectual disabilities explained that family members often took decisions on their behalf or exercised control over their daily activities:

“My family put me in the place I am living today.”

(Woman with mental health problems, 34, Greece)

“My dad influences me in many things, he supports me financially, and due to that [...] he does not let me [...] be independent, [...] be myself. I am under his influence. If I do not obey, he threatens me with taking back the support from my children. This is a terrible situation; I simply cannot assert myself.”

(Woman with mental health problems, 36, Hungary)

“My mother does not let me go anywhere alone, because I do not know [the town].”

(Woman with intellectual disabilities, Greece)

“My budget goes in the family’s budget, my sister deals with the money, she buys what we need in the house. [...] I don’t have pocket money, but if I need anything I talk with my sister and she gives me according to the budget level.”

(Man with mental health problems, 41, Romania)

“I stay mainly in my room. My mother goes shopping [...], my mother does the laundry [...], my mother cooks [...]. When I go to see my friends she gets worried and rings me up on the phone several times.”

(Man with mental health problems, 43, Bulgaria)

Interviews with participants with mental health problems in Germany who had particularly close links to their families indicated that relatives took care of their personal matters, either as informal support or through a written power of attorney.

Marriage, relationships and having children

A number of respondents with mental health problems said that their parents tried to influence their choices about relationships, and having and looking after children:

“The doctor told me that I have schizophrenia and it’s best that I don’t have babies, and suggested that I have an abortion [...] my parents took me. [...] I wanted to keep the baby.”

(Woman with mental health problems, 43, Romania)

“[My mother] thought about temporarily revoking my rights to care for my child because I hadn’t been looking after the child during my first days in hospital. If I had stayed longer in hospital, maybe some of my rights would have been taken away.”

(Woman with mental health problems, 26, Latvia)

In contrast, other interviewees reflected on the complexity of their parents’ involvement in their personal lives. A respondent in Hungary said that her family found it difficult to accept her growing independence:

“We had a big argument about this [...]. I had some relationships previously and a few times my partner was only after things I had and did not love me for who I am. And of course my family was only trying to protect me. I told my mum about this guy and that he was different. I told her not to judge him before getting to know him. [...] Then my younger brother told me that our parents were not against me but that they only love me and want to protect me and for me to be safe with somebody when they are no longer around.”

(Woman with intellectual disabilities, 30, Hungary)

Healthcare and psychiatric treatment

A number of respondents with mental health problems said that a lack of information and the close involvement of family members in the treatment process had hampered their ability to take decisions regarding healthcare and psychiatric treatment:

“From the bottom of my heart, I wish that my psychiatrist would tell me my diagnosis and what treatment I am getting. [...] I have never been told. For at least the last 10 years I have wished to talk to someone about it.”

(Woman with mental health problems, 39, Romania)

“My parents never fully informed me about my condition.”

(Woman with mental health problems, Greece)

“When I was transferred to a private clinic, my aunt told me I was going to a hotel.”

(Woman with mental health problems, 48, Greece)

Respondents also discussed the particular challenges presented by situations where parents are the point of contact with medical staff. A man in Romania, for instance, said that his mother had not told him the name

or side effects of his medication, while a woman in Greece said that she did not know her first doctor and that her mother gave her all her medication:

“My mother didn’t tell me about the treatment’s side effects. [...] Unfortunately, I felt them by myself. [T]he medicine I was taking, it made me feel intoxicated, dizzy.”

(Man with intellectual disabilities, 30, Romania)

The close relationship between parents and medical professionals led one respondent in Hungary to believe mistakenly that she was under guardianship when in fact she retained full legal capacity:

“My mum has been my guardian for three years now and really if mum doesn’t have time to come with me and I go to the psychiatric hospital on my own then the doctor complains right away saying that I should not do this because my mother has to come as well [...]. Also, if the local hospital advises me to stay, they always need mum to sign so that she approves of me being admitted to the hospital.”

(Woman with mental health problems, 27, Hungary)

3.3. Experiences of supported decision-making

As Article 12 (3) of the CRPD sets out, persons with disabilities may require support to exercise their legal capacity and take decisions about their lives. Both participants with mental health problems and participants with intellectual disabilities discussed their experiences of a range of different aspects and types of support including: the availability of support; support from professionals, NGOs and advocacy organisations; and support from family and friends.

3.3.1. Availability of support for decision-making

Participants in this research had a variety of types of supported decision-making available to them, as outlined in the FRA report *Choice and control: the right to independent living*.²⁶⁴ In addition to informal assistance to take decisions, such as support from family and friends for participants from all nine EU Member States, a number of participants from Sweden had more formal arrangements in place to aid the decision-making process. Three respondents in Sweden with intellectual disabilities – but none with mental health problems – had a contact person, while two interviewees with mental health problems had previous experience of a personal agent. Support was, according to the participants, given in contact with authorities and welfare agencies, and in relation to financial affairs and housing problems. All of the respondents who had benefited from this type of support reported very positive experiences.

²⁶⁴ FRA (2012b).

Examples of support to exercise legal capacity

EU Member States offer a variety of supported decision-making schemes. The following is not an exhaustive list but reflects instead the experiences of participants in the FRA fieldwork research.

Germany:

Custodianship: Courts appoint custodians (*Betreuer*) and a yearly review is required with the individual concerned in attendance. The appointment of a custodian does not in itself have an immediate effect on the person's legal capacity and contractual ability, e.g. on the person's right to marry or to make a will or on the parental right of custody.

For more information on custodians, see: www.gesetze-im-internet.de/englisch_bgb/englisch_bgb.html#p0025

Sweden:

Contact person: A contact person is one of the 10 services designated by the Law on Special Support and Services for Persons with Disabilities (*Lag om stöd och service till vissa funktionshindrade*) as specific social rights. A contact person is a companion who can help the individual to lead an independent life by reducing social isolation, helping him or her to take part in recreational activities and providing advice in everyday situations. This support can sometimes be provided by a family, known as a support family.

Personal agent: Personal agents (*personligt ombud*), a role also translated as 'personal ombudsman', represent and help people with mental health problems to deal with other agencies and the healthcare system. They are led by the client's wishes, needs and rights, and ensure that the various welfare agencies plan, coordinate and carry out their measures. Personal agents work in the client's home or natural social environment with the aim of providing the user with practical help to manage their daily life. Personal agents also play a role in highlighting general systemic shortcomings in the work modes of personal service organisations and problems in the division of labour between such organisations that may affect users in a negative way.

For more information on contact persons, see: www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8407/2009-126-188_2009126188.pdf

For more information on personal agents, see: National Board of Health and Welfare (*Socialstyrelsen*) (2000) *Statsbidrag till kommuner för uppbyggnad av verksamheter med personliga ombud*. Meddelandeblad 14/2000; Sweden/ National Board of Health and Welfare (*Socialstyrelsen*) (2002) *Mål och metoder. Att arbeta som personligt ombud*. Kunskapsöversikt; See also: <http://personligtombud.se/>

United Kingdom:

Independent mental health advocate (IHMA): Established under mental health legislation, IHMAs help and support qualifying patients to understand and exercise their legal rights. They are available to most detained patients as well as to people with mental health problems who are subject to supervised community treatment orders or guardianship. The person or organisation appointing persons as IMHAs must ensure that they have the appropriate experience and training.

Independent mental capacity advocate (IMCA): The role of the IMCA is to represent and support people at times when critical decisions are being made about their health or social care. They are mainly involved when persons are deemed to lack capacity to make these decisions themselves and they do not have family or friends who can represent them. The IMCA will bring to the attention of the decision-makers all factors that are relevant to their decision. If appropriate, IMCAs are able to challenge the decision-maker.

Person-centred planning: Person-centred planning is a set of approaches designed to assist persons with intellectual disabilities to plan their lives and to support them by asking what they want, what support they need and how they can get it. It focuses on the positive aspects of people's lives rather than on assessing what they cannot do.

Circles of support: A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody (the 'focus person') accomplish their personal goals in life. The focus person is in charge of deciding both whom to invite to be in the circle and also the direction in which the circle's discussions move, although a facilitator is normally chosen from within the circle to handle the work required to keep it running. The members of the circle of support, which may include family, friends and other community members, are not paid.

For more information on IHMAs, see: www.legislation.gov.uk/ukxi/2008/3166/contents/made and www.nmhd.org.uk/silo/files/independent-mental-health-advocacy-guidance.pdf.

For more information on IMCAs, see: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131963.pdf and www.ic.nhs.uk/services/mental-health/using-the-service/datasets-databases-and-data-collections/mental-capacity.

For more information on person-centred planning, see: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_115249.pdf.

For an example of circles of support, see: www.circlesnetwork.org.uk/home.asp?slevel=oz&parent_id=1



Participants from EU Member States which have supported decision-making schemes complained about a lack of resources, which results in an uneven distribution of such formal support services. One interviewee with mental health problems in Sweden, for example, explained that his caseworker from social services helped him to apply for a care allowance because there were no personal agents available in his district.

In many other EU Member States, however, participants spoke of a lack of available support for decision-making. None of the interviewees with intellectual disabilities in Greece, for instance, had experience of supported decision-making schemes, while the interviews with stakeholders and people with mental health problems in Latvia indicated that a national system for support in decision-making has not been established. Both respondents with mental health problems and intellectual disabilities in Romania reported that they did not know of any alternatives to guardianship and stakeholders agreed, saying state authorities had not adopted any procedures designed to help people with intellectual disabilities to take decisions.

The lack of formal support options left many participants dependent on their families and friends. Stakeholders participating in the mental health focus group in Bulgaria, for example, reported that parents and other relatives are the only source of support for persons with disabilities when taking decisions. Some social service representatives said that they support their clients in taking certain decisions but acknowledge that they do not do so consistently.

Stakeholders and respondents discussed a number of factors that can influence the opportunities for persons with disabilities to access support for decision-making. Respondents in Latvia noted that living arrangements can have a major impact: persons with mental health problems and persons with intellectual disabilities living in group apartments were seen to be in a better position to access support in taking decisions than those living elsewhere. Participants in the United Kingdom noted that people who did not have good support from family and friends were more likely to seek formal sources of support. Lack of awareness of available decision-making support options also emerged as a theme, indicating the importance of ensuring that information about such services is communicated and made accessible for persons with disabilities.

3.3.2. Support from professionals, NGOs and advocacy organisations

Participants with mental health problems or intellectual disabilities from Latvia, Sweden and the United Kingdom spoke of receiving professional support in decision-making – including from social workers as well as

from specialist decision-making supporters, such as NGOs and advocacy organisations. Most participants valued this experience highly:

“[My personal agent] learned a lot about me and my needs. He was a person who listened to me and we still keep in touch.”

(Man with mental health problems, Sweden)

“Sometimes I ask [the group home’s head] for advice on something, but it is not like she makes the final decision. Or I ask the support person if it is a matter I do not want others to know about. [...] Everyone has a support person. You could even choose which person you trusted the most.”

(Woman with mental health problems, 47, Latvia)

A woman with intellectual disabilities from Sweden explained how she had been on trips and taken part in other activities with her contact person:

“She is like my friend, I don’t think very much about not having friends of my own age.”

(Woman with intellectual disabilities, 29, Sweden)

Respondents stressed the importance of being able to choose between different sources of decision-making support. Several interviewees in Latvia said that they preferred receiving assistance from a professional, such as a social worker, rather than from family members who might be too personally involved in the situation. Commenting on the most appropriate person to provide support, a Latvian interviewee responded:

“A professional, because unfortunately with relatives [...] in my experience, they do what is best for themselves [...] and he [a relative] did me wrong, I can say that.”

(Respondent with mental health problems, Latvia)

Stakeholders in Latvia, however, said that, although possible conflicts of interest meant family members were not ideal support people, professional support providers currently lacked capacity. Representatives from NGOs said that there should be a gradual transition to professional support, but only if the support staff were sufficiently qualified.

Participants from several EU Member States emphasised the positive role self-advocacy and service user-led groups often played. A number of respondents with intellectual disabilities from the United Kingdom had links to self-advocacy support services, which they valued more highly than traditional services. Stakeholders taking part in the focus group on mental health in Hungary said self-help groups could significantly improve the motivation of persons with disabilities to take decisions independently.

Other respondents reflected on how supported decision-making processes could be designed to meet their

individual needs. Some spoke about the importance of developing a flexible system that responded to the fluctuating nature of mental health problems. One respondent explained that she was generally able to take decisions independently, and wanted a system that could provide her with support during periods when her mental health problems worsened:

"It was very hard for me at that time [when her illness worsened] to take decisions, for example on whether or not to fight for my apartment. I did not know who to turn to."

(Woman with mental health problems, 40, Latvia)

Stakeholders taking part in the focus group on intellectual disability in the United Kingdom said that authorities often thought that legal advocacy was required, when people with disabilities more frequently preferred someone to explain complicated issues and assist with reaching a decision. Better signposting of available services might help people to get the help required.

Moreover, stakeholders on intellectual disability in Sweden reported that the qualifications and commitment of mentors and trustees varied considerably, meaning that some people with intellectual disabilities were unable to exercise their right to supported decision-making.

3.3.3. Support from family and friends

Both respondents with intellectual disabilities and participants with mental health problems referred to the significant decision-making support family and friends provided. Many participants who had good relationships with family and friends relied primarily on their guidance and, in situations where they felt unable to take decisions on their own, took decisions after consulting with relatives:

"My wife's opinion is most important. Then come those of myself, and perhaps my father, mother or brother, in that order. [...] I always carry my mobile phone with me, and in any situation in life we [the respondent and his wife] call each other."

(Man with mental health problems, 47, Latvia)

"Yes, my family supports me, I couldn't manage by myself, but my aunt would also help me, for example. [...] So, yes, I consider my family gives me my main support."

(Woman with mental health problems, 42, Romania)

"I ask my mother if I do not understand something [...], if you understand it all yourself, then it is not necessary. If you do not understand something, then let her [...] do it for you."

(Man with intellectual disabilities, 38, Latvia)

Several participants highlighted the role of friends and staff at their group apartments or day centres in providing advice on what to do:

"[My friend at the group apartment] is like my grandfather, and I always ask him for advice. I ask his advice on what to do and what not to do."

(Man with intellectual disabilities, 31, Latvia)

Conversely, most participants with intellectual disabilities in Romania relied entirely on the support and advice of their family or service coordinator when decisions had to be taken, and said they would not ask for a second opinion from the staff of the centres they attended.

For other respondents the importance of relatives and friends in the decision-making process reflected their dependence on family members. All of the respondents with mental health problems in Greece mentioned that they discussed with their families the important decisions regarding their lives, such as the decision on their place of residence, how to spend money, where to go on holidays, whom to meet or whether to continue with pharmaceutical treatment. Stakeholders, however, cautioned that family might on some occasions hinder the recovery of the person with mental health problems.





The way forward

This report analyses current legal standards and safeguards in the area of legal capacity for persons with disabilities against the backdrop of the individual stories of those whose lives they most directly affect. The comparative legal analysis illustrates the large variety of relevant laws and procedures in the 27 EU Member States, and highlights points of tension between existing national legal frameworks and the standards set out by the CRPD. The wide-ranging consequences of restrictions on legal capacity described by the participants in the fieldwork element of this research underline the importance of developing models which promote the independence and autonomy of persons with disabilities in line with the CRPD.

The issue of legal capacity presents a particular challenge for EU Member States as they attempt to harmonise their legal frameworks with CRPD requirements. It has relevance and repercussions across all areas of life, spanning such diverse issues as signing a contract of employment, deciding whether to have children and taking decisions regarding healthcare treatment. Moreover, the CRPD's rights-based approach to disability, and in particular its focus on placing people at the centre of all decisions affecting them, represents a significant departure from previous conceptions of the role and scope of legal capacity legislation.

The application and implementation of the CRPD's legal capacity standards continues to stir debate. To provide firm guidance on interpreting this area of the convention, the CRPD Committee's jurisprudence must develop further. Thus far, though, the CRPD Committee's concluding observations forcefully underline the convention's guarantees, which would support calls to abolish or overhaul national legislation that allows for substituted decision-making models and replace them with supported decision-making measures that respect the person's autonomy, will and preferences. This

report's legal analysis illustrates some of the particular challenges facing the EU Member States that are already beginning the process of reforming their legal capacity legislation to reflect this interpretation.

The abolition of substituted decision-making regimes will require the development of alternative mechanisms to support those persons with disabilities who may need assistance with taking decisions. The findings of the fieldwork research highlight how such schemes are already empowering persons with disabilities to exercise their ability to take decisions about their lives. These experiences point to the need to investigate how mechanisms other than those based on substituted decision-making can be established on a national scale. To be sustainable, such measures will necessitate coordination between service providers, local officials and existing support schemes. In keeping with the CRPD ethos of 'nothing about us without us', they will also require the participation of persons with disabilities and their representative organisations, as well as the involvement of the user-led organisations and self-advocacy groups which often help persons with disabilities to build up the skills and confidence required to take decisions.

The EU does not have specific competence to address questions regarding the legal capacity of persons with disabilities. Nevertheless, it can play a major role in assisting Member States in the process of ensuring the conformity of their legislation on legal capacity with the CRPD, for example by providing forums to exchange experiences. Moreover, as legal capacity is increasingly framed as an issue rooted in the principles of non-discrimination and equality, it becomes of greater relevance to EU law and policy. The further development of EU law and policy, particularly in the area of non-discrimination, could therefore play a role in the process of harmonising legal capacity legislation with the CRPD across the EU.

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Annex: Legislation on legal capacity

EU Member State	Legislation	Last significant amendment
AT	Federal Law on Guardians for Disabled Persons (<i>Bundesgesetz über die Sachwalterschaft für behinderte Personen</i>) Civil Code (<i>Allgemeines bürgerliches Gesetzbuch</i> , ABGB) Non-Contentious Proceedings Act (<i>Außerstreitgesetz</i> , AußStrG)	Amendment to the Guardianship Law 2006 (<i>Sachwalterrechts-Änderungsgesetz 2006</i> - SWRÄG 2006)
BE	Civil Code (<i>Code Civil</i>) Judicial Code (<i>Code Judiciaire</i>)	18 July 1991
BG	Persons and Family Act (<i>Закон за лицата и семейството</i>) Family Code (<i>Семеен кодекс</i>) Civil Procedure Code (<i>Граждански процесуален кодекс</i>)	1 October 2009
CY	Law on administration of property of persons incapable of administering their property and affairs and for the control of the administration (23(I)/1996) (<i>Ο περί Διαχείρισης της Περιουσίας Ανίκανων Προσώπων Νόμος του 1996</i>) Law on the Rights of Mentally Retarded Persons (117/1989) (<i>Ο περί Νοητικά Καθυστερημένων Ατόμων Νόμος του 1989</i>)	
CZ	Civil Code, Act no. 40/1964 (<i>Občanský zákoník, Zákon č. 40/1964 Sb.</i>) Civil Procedure Code, Act no. 99/1963 (<i>Občanský soudní řád, Zákon č. 99/1963 Sb.</i>)	1 January 2012; comes into force as of 1 January 2014
DE	Civil Code (<i>Bürgerliches Gesetzbuch</i> (BGB)) Law on Procedure in Family Affairs and in Matters of Voluntary Jurisdiction Reform Act (<i>Gesetz zur Reform des Verfahrens in Familiensachen und in Angelegenheiten der freiwilligen Gerichtsbarkeit</i> (FGG-RG)) Third Act Amending the Custodianship Act (<i>Drittes Gesetz zur Änderung des Betreuungsrechts</i>)	1 September 2009 1 September 2009
DK	Act on Guardianship (<i>Værgemålsloven</i> , n. 1015/2007)	
EE	General Part of the Civil Code (<i>Tsiviilseadustiku üldosa seadus</i>) Code of Civil Procedure (<i>Tsiviilkohtumenetluse seadustik</i>)	
EL	Civil Code (<i>Αστικός Κώδικας</i>)	
ES	Civil Code (<i>Código Civil</i>) Civil Procedure Act (<i>Ley de Enjuiciamiento Civil</i>)	
FI	Government Bill HE 146/1998 (<i>Hallituksen esitys Eduskunnalle holhouslainsäädännön uudistamiseksi</i>) Guardianship Services Act (<i>laki holhoustoimesta/lag om förmyndarverksamhet</i> (442/1999))	
FR	Civil Code (<i>Code Civil</i>)	Act No. 2007-308 of March 5 reforming legal protection of adults
HU	Act IV of 1959 on the Civil Code of the Republic of Hungary (<i>Az 1959. évi IV. törvény a polgári törvénykönyvről</i>)	New Civil Code to enter into force in 1 January 2014
IE	Lunacy Regulation (Ireland) Act	
IT	Civil Code (<i>Codice Civile</i>) Code of Civil Procedure (<i>Codice Di Procedura Civile</i>)	Law n.6, 9 January 2004
LT	Civil Code (<i>Civilinis Kodeksas</i>) Code of Civil Procedure (<i>Civilinio proceso kodeksas</i>)	No XI-1312, 12 April 2011

EU Member State	Legislation	Last significant amendment
LU	Law on legally incapable adults (<i>Loi du 11 août 1982 portant réforme du droit des incapables majeurs</i>)	
LV	Civil Code (<i>Latvijas Republikas Civillikums</i>) Civil Procedure Code (<i>Civilprocesa likums</i>)	Amendments to the Civil Law (<i>Grozījumi Civillikumā</i>), 29 November 2012 (in force from 1 January 2013) Amendments to Civil Procedure Code (<i>Grozījumi Civilprocesa likumā</i>), 29 November 2012 (in force from 1 January 2013)
MT	Civil Code (<i>Civili kodiči</i>) Code of Organization and Civil Procedure (<i>Kodiči ta 'organizzazzjoni u proċedura ċivili</i>)	XXIV of 2012 – Code of Organization and Civil Procedure and the Civil Code (Amendment) Act, 7 December 2012
NL	Civil Code (<i>Burgerlijk Wetboek</i>)	
PL	Civil Code (<i>Kodeks cywilny</i>) Code of Civil Procedure (<i>Kodeks postępowania cywilnego</i>)	
PT	Civil Code (<i>Código Civil</i>) Code of Civil Procedure (<i>Código de Processo Civil</i>)	
RO	Civil Code (<i>Codul Civil</i>)	New Civil Code (<i>Legea 287/2009 Noua Cod Civil</i>), 17 July 2009
SE	Code on Parenthood and Guardianship (<i>Föräldrabalk 1949:381</i>)	9 June 2005
SI	Code of Obligations (<i>Obligacijskega zakonik</i>) Non-litigious Civil Procedure Act (<i>Zakon o nepravdnem postopku</i>) Marriage and Family Relations Act (<i>Zakon o zakonski zvezi in družinskih razmerjih</i>)	Amendments in Mental Health Act No. 77/2008 (<i>Zakona o duševnem zdravju</i>), 23 July 2008
SK	Civil Code (<i>Občiansky zákonník – Zákon č. 40/1964 Zb.</i>) Civil Procedure Code (<i>Občiansky súdny poriadok – Zákon č. 99/1963 Zb.</i>)	
UK	Mental Capacity Act 2005 Mental Health Act 1983 Adults with Incapacity (Scotland) Act 2000 Enduring Powers of Attorney (Northern Ireland) Order 1987	Mental Health Act 2007



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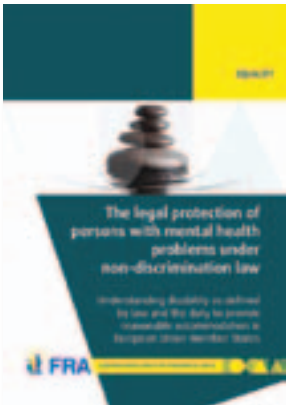
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These four reports provide analysis of issues relating to the rights of persons with mental health problems and persons with intellectual disabilities.



HELPING TO MAKE FUNDAMENTAL RIGHTS A REALITY FOR EVERYONE IN THE EUROPEAN UNION

Equal recognition of persons before the law is a long-established human rights principle. Nevertheless, legal frameworks in many European Union (EU) Member States allow for the legal capacity of persons with intellectual disabilities and persons with mental health problems to be restricted or removed under certain conditions. These legal frameworks are now undergoing a transformation as the entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) drives rapid and significant change across those states that have ratified the convention, including 24 EU Member States and Croatia as well as the EU itself. Based on a rights-based approach to disability, which puts individuals at the centre of all decisions affecting them, the issue of legal capacity is being reframed in terms of the support that persons with disabilities may need to make decisions. This report by the EU Agency for Fundamental Rights (FRA) analyses the current legal standards on legal capacity across the EU, set against the backdrop of the experiences of interviewees who have had their legal capacity removed or restricted. The FRA report reveals the gap between the promise of the CRPD and the reality those with disabilities face in the EU every day, and, by so doing, hopes to contribute to closing it.



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