Legal Capacity in Europe



A Call to Action to Governments and to the EU



Mental Disability Advocacy Center

Hercegprímás utca 11 H-1051 Budapest Hungary

T: +36 1 413 2730 F +36 1 413 2739 E: mdac@mdac.info W: www.mdac.info

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Foreword

In our daily lives, many of us take for granted the right to make decisions about our lives – how to spend our money, where and with whom to live, and which doctor or medical treatment to receive when we are unwell. However, for many people with intellectual disabilities and people with psycho-social (mental health) disabilities, these basic decision-making rights are removed through the operation of guardianship systems. In many jurisdictions, the restriction of a person's legal capacity also has the result of denying their recognition before the law, meaning they have no recourse even to challenge decisions made on their behalf.

The essence of all guardianship systems is a model of substituted decision-making – removing the power from people with disabilities to make legally-recognised decisions and giving this to someone else. Such systems of guardianship frequently rely on an image of people with disabilities being either incapable of making decisions (an extremely rare situation in reality) or paternalistic notions that they might make 'bad decisions'. Yet, all of us make decisions in our lives which other people are likely disagree with – and restricting our right to make these would be unthinkable on the most part.

During my six-year mandate as Commissioner for Human Rights of the Council of Europe, I met numerous people who had been deprived their legal capacity, right across the continent. To shed light on this, I published an extended analysis on the right to legal capacity last year. It remains my view that the right to legal capacity is one of the most invisible human rights issues in Europe today, and is also one of the most important. Too many people with disabilities are denied the right to make choices in their lives. Too few are provided access to seek redress through legal mechanisms. And too many countries are not doing enough to remedy this situation.

Having ratified the United Nations Convention on the Rights of Persons with Disabilities, the European Union (EU) must play a more proactive role than it has done so far. The primary duty of realising the human rights of people with disabilities falls upon Member States. EU institutions also have an obligation to ensure not simply coordination at the European level, but action where there are EU competences. This report contributes a push in that direction.

On behalf of MDAC, I encourage those who work for governments or the EU, to take their obligations seriously. Be bold, be innovative, and be courageous. But above all, take action.

Thomas Hammarberg
MDAC Honorary President

Commissioner for Human Rights of the Council of Europe, Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities, 20 February 2012, CommDH/IssuePaper(2012)2, available at: https://wcd.coe.int/ViewDoc.jsp?id=1908555 (last accessed: 8 Oct 2013).



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Chapter 1: Roadmap and purpose of the report

This report consists of eight chapters. The purpose of it is to call on governments and the institutions of the European Union to take concrete law and policy actions so that all people with disabilities have their right to legal capacity, and have access to supports to exercise it.

The present chapter sets out a roadmap of the report, and explains why MDAC has written it. At a conference last year in Poland, a Polish self-advocate (a person with intellectual disabilities) told us what freedom meant to him: "People with disabilities should make their decisions on their own regardless of whether the decision is good or bad." The lives of people with disabilities, as told by people with disabilities, is what motivates us to help policy-makers imagine a different system and get to work creating one. Many of these policy-makers interact with people with disabilities, their organisations, and advocacy organisations such as MDAC. They demonstrate policy leadership and because of this, there is real progress in some countries. But some governments are doing nothing. One of the reasons for this is that there is little information about what exactly the requirements of international law are, and how in practical policy terms reforms can be undertaken.

In September 2013 the UN Committee on the Rights of Persons with Disabilities (CRPD Committe) published a draft general comment on legal capacity. While this report is not intended as a formal response to the draft general comment, it does aim to speak to it, and supplement information by sharing MDAC's understanding of legal capacity and our experiences of advocacy and litigation.

Chapter 2 sets out why guardianship is a failed system in dire need of reform. It looks at the lives of people under guardianship and suggests that a system which systematically strips away people's personhood is unfit for purpose. The chapter outlines some of the cases which MDAC has litigated in various countries to show how the system is itself a human rights violation, and how it causes further abuse and neglect.

Chapter 3 sets out a vision of a world of equality and inclusion. This vision is neither new nor existing. Inclusion is actually quite dull and ordinary because all it means is treating people with respect. It can, however, have a transformative effect on people's lives. The chapter looks at Article 12 of the UN Convention on the Rights of Persons (CRPD) which is the provision setting out the right to legal capacity on an equal basis with others. It looks at the various forms of supports which States should make available for people who need them. It explains how people with disabilities must no longer be treated as incapable objects of pity, but subjects of human rights on an equal basis with others.

It also contains some data on guardianship in Europe. It is not the role of groups such as MDAC to report on how many people are under guardianship: that is the role of government. But it is the role of non-governmental organisations to point out where data is missing, and to try and understand the meaning of data, if that is possible. The chapter points out that data is sketchy, and the data which exists shows a massive variance of how



guardianship is applied. In Bulgaria, for example, around 100 per 100,000 population are under guardianship, whereas the figure in the guardianship champion of Europe (Hungary) is 596. The second important finding of the chapter is that in jurisdictions where partial guardianship is available, total guardianship is most often used. We presume this is because it is simply more convenient for doctors, lawyers, judges, carers and families.

The CRPD Committee has recently confirmed in its draft general comment that Article 12 of the CRPD is a civil and political right. As such, it must be implemented by all governments immediately. There is urgent law reform work to be done, and Chapter 4 speaks directly to governments. The requirements established by the CRPD Committee are examined, and we offer some advice to governments about the provisions which they could consider adopting in legislation to give practical effect to the CRPD obligations. In a nutshell, law needs to set out the recognition of legal capacity and each person's right to exercise it, as well as a range of supports which people with disabilities can access when exercising their legal capacity.

Civil society organisations are sometimes key partners for governments. Non-governmental organisations can play a useful advocacy role to hold governments to account. Chapter 5 lays out some of the learning which MDAC has gathered over the last few years as we have interacted in various ways with non-governmental organisations and governments in eleven European countries. The chapter outlines the need to look across an array of legislation, strengthening the advocacy capabilities of people with disabilities, reporting on stigma, abuse and neglect, the tensions between suggesting a revolution versus framing advances as an evolution, how to respond to governmental austerity, and how to encourage politicians to jump on board a reform agenda.

Turning to the institutions of the European Union, Chapter 6 argues that the EU's ratification of the CRPD requires far more substantial action than simply coordinating the actions of Member States. The obligations of EU institutions are examined in some detail and this part of the report explains that the institutions of the EU must lead the way. It is a sad reflection of the current approach that people with disabilities who have had their right to legal capacity restricted or denied cannot even vote in European elections. This only increases the democratic deficit between the citizen and the Union, and the EU must reverse this path.

Chapter 7 of the report, the most substantial in terms of size, provides a snapshot of legal capacity law reform processes in 16 European jurisdictions. These are the countries where MDAC has been involved in advocating for legal capacity law reform, in partnership with numerous representatives of European civil society organisations. Perhaps one of the most telling things about the country reports are the variety of different reforms currently in process. There are examples of jurisdictions where reforms are piecemeal, incomplete or lacking in compliance with the requirements of Article 12 of the CRPD. There are examples where governments have engaged with civil society organisations and have led the way in legal capacity reform: the Czech Republic, while the result of their law reform is not perfect, is clearly a good example.



Why is there a need for this report?

MDAC was established in 2002 to use the law to fight for inclusion and equality for people with intellectual disabilities and people with psycho-social (mental health) disabilities. It did not take the organisation long to realise that people under guardianship were – through the very operation of law – denied even the most basic rights: to decide where to live, to decide when to get up in the morning, what to eat, where to go on holiday. We found that many rights were taken away altogether. People's signatures were invalid, meaning that they could not sign employment contracts: ridiculous given that many people with disabilities live in poverty, denying them access to the labour market. Their right to vote was stripped away, so that they became politically invisible. Their right to demand justice, to shake off the cloak of guardianship, was denied. As a legal advocacy NGO, it was clear to MDAC that it had to adopt legal capacity as a focus for its litigation, monitoring and advocacy. We set about a campaign to validate people's existence through the law.



In 2006, the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) was adopted. It was a milestone in the evolution of human rights. For the first time, international law provided a clear nudge away from regimes of substituted decision-making like guardianship, towards systems based on support. While in a guardianship system, the legal capacity of a person can be denied or restricted, in the support system the person's legal capacity remains intact and s/he gets support from trusted individuals to make choices. Although there is an obligation on States under the CRPD to review and amend their legal capacity legislation, the text is unclear about the policy and legislative steps which are required to get from one 'paradigm' to the other. There is a lack of knowledge on legal capacity law reform initiatives, as there is about promising practices on the ground.

That said, there is now more international focus on the need to carry out legal capacity law reform than ever before.

Thomas Hammarberg, who wrote the Foreword of this report, was from the Commissioner for Human Rights of the Council of Europe from 2006 until 2012. He released an issue paper in October 2008 on human rights and disability, in which he discussed the right of persons with disabilities to make decisions for themselves.³ He observed that "the focus [of Articles 3 and 12 of the CRPD] is on enabling people to make and communicate their decisions. It builds on the sound belief that everyone can make choices and communicate them to others, while recognising that sometimes this requires support". He emphasised that independence and autonomy are "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".

² Rusi Stanev won his case at the European Court of Human Rights in January 2012. Read more about his case in Chapter 2.

³ Thomas Hammarberg, "Human Rights and Disability: Equal Rights for All", Council of Europe, October 2008, CommDH/ IssuePaper(2008)2, sec. 5.



In 2009, one of Thomas Hammarberg's "Viewpoints" focused on the rights of persons with intellectual disabilities. The Commissioner stated that, "Little is also being done to develop a wise and rights-based approach to the problem of the legal capacity of those with intellectual disabilities. It may be in the nature of this impairment that problems occur in relation to how one represents oneself towards authorities, banks and other such institutions. This, however, is no justification for a policy to routinely incapacitate people with mental disabilities and put them under legal guardianship where they have no say in important decisions affecting their lives."

In February 2012 Thomas Hammarberg published a further issue paper entitled "Who Gets to Decide?" on the right to legal capacity. Among the recommendations was that States should "abolish mechanisms providing for full incapacitation and plenary guardianship", ensure that people with disabilities enjoy all fundamental rights and review judicial procedures that allow for restriction of legal capacity. He also recommended that States develop supported decision-making systems and "establish robust safeguards" that ensure the supports provided are at the selection of the individual, and that people with disabilities and their representative organisations should be involved in the legislative reform process. He emphasised that "reforming current mechanisms for legal capacity is one of the most significant human rights issues in Europe today". Reform is necessary for three reasons, he said. First, legal capacity concerns "what it means to be human". Second, its deprivation affects a huge number of Europeans with intellectual disabilities and those with psycho-social disabilities. And third, "a label of incompetence can easily become a self-fulfilling prophecy"; that is to say, if a person does not have the chance to exercise independent decision-making, he or she can never learn to do so. The report called for "no less than a radical overhaul of present policies."

In July 2013 the European Union Agency for Fundamental Rights (EU FRA) issued a report on legal capacity, ⁵ the culmination of a two-year research project which MDAC was involved in coordinating. The report sets out an analysis of international and European legal standards and usefully compares the legal capacity laws in European Union Member States, and like this report, makes the point that the CRPD has been the driver of significant change. Significantly, the report details evidence from fieldwork undertaken in nine countries. First-hand testimonies from people with disabilities themselves highlight the legal capacity obstacles which people face in getting on with their lives. The report suggests to governments "to replace decision making by others on behalf of people with disabilities with decision making by people with disabilities guided by others; this will respect the autonomy, will and preferences of people with disabilities", to ensure support for people with disabilities who may need assistance with taking decisions, and conformity of legal capacity laws and policies with the CRPD.

⁴ Thomas Hammarberg, "Who Gets to Decide?", Council of Europe, February 2012, CommDH/IssuePaper(2012)2.

⁵ European Union Agency for Fundamental Rights, "Legal capacity of persons with intellectual disabilities and persons with mental health problems", July 2013.



In September 2013 the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) released its long-awaited draft general comment on Article 12 of the Convention. This document sets out the preliminary thinking of the CRPD Committee, to whom governments and NGOs alike are turning for authoritative statements. It is MDAC's intention that this report feeds into the process of both the adoption of a final general comment, and into deeper discussions of law and policy reform at the country-level as well as at the European and indeed global levels.

Most people are allowed to make extremely foolish life decisions without facing government intervention. You can choose to smoke until you die. You can eat so much that you cannot get through the doorway to leave your home. Being a member of a recognised religion allows you to make a health decision based on a tenet of your religion even if you may put your life in danger.

But if you are a mental patient, there is an automatic bias to believe that you are incapable of making good decisions. Therefore, it is necessary for the court to determine what is in your best interest regardless of your beliefs. The freedom to make poor choices is a privilege that is denied to the person who is labeled mentally ill.

Ronald Bassmann⁶

The Community Consortium, Mental Illness and the Freedom to Refuse Treatment: Privilege or Right. In: Professional Psychology: Research and practice, 2005, Vol. 36, No. 5, at page 491. Available at: http://ronaldbassman.com/pdfs/Freedom%20to%20 Refuse.pdf (last accessed: 8 Oct 2013).



What is legal capacity and why is it important?

Deciding things in our life is pretty mundane. We rarely consciously realise we are making decisions, let alone step back to reflect on the importance of having the freedom to make these decisions, and accessing support to do so. We get up in the morning, decide what to wear, what to have for breakfast, and how to get to where we need to go. We can decide on whether to meet our friends and when and where to go with them and what to do. We make decisions on whether to have a shower or a bath before going to bed. We can also decide on whether or not to get married, have children or whether to have a cheese or a ham sandwich.

This is not the case for people labelled with intellectual disabilities and people labelled as having a mental illness (which we refer to as 'psycho-social disabilities'). They are often placed under someone else's decision-making authority. This is possible because in many countries people with disabilities can be deprived of their legal capacity.

Legal capacity is a legal construction which consists of two components, namely the capacity to have rights and the capacity to act. While the former element is about acknowledging that the individual can be holder of rights and obligations, the latter is about exercising these rights and undertaking duties. This means for example that if an adult is deprived of their legal capacity, she may be owner of her house but she is prohibited from selling it or putting it in her will.

She becomes a non-person in the view of the law. She is plunged into civil death.

Although guardianship is supposed to protect the rights and interests of people with disabilities, it is a system that gives greater precedence to the interests of third parties: relatives, carers, bank clerks doctors and so on. Guardianship laws do not protect people against abuse; they cause it.⁷

⁷ For example, in 2007-8 MDAC released in-depth reports on guardianship and human rights in Bulgaria, Czech Republic, Georgia, Hungary, Kyrgyzstan, Russia and Serbia. These were the first reports which framed guardianship as a human rights concern. In 2011 MDAC published a report on human rights in psychiatric hospitals and social care institutions in Croatia which addressed the link between deprivation of legal capacity and denial of the right to live in the community.



103. Further, in the present case the guardian appointed to the second applicant was given a wide range of powers, such as representing her in all personal matters and matters concerning her property, managing her assets and taking proper care of her person, rights, obligations and well-being. The Court therefore considers that the institution of the proceedings with a view to divesting the second applicant of legal capacity amounted to an interference with her private life within the meaning of Article 8 of the Convention [on the right to a private and family life].

[...]

115. The applicant in the present case, when heard by the national authorities, explained that she lived alone and had taken care of all her needs. She stressed that she regularly paid all her bills, was seeing regularly her general physician, had taken care of her meals and organised her social life. Further to her statements, the Court notes that there is no indication, either before the institution of the proceedings in question or during them, of specific damage that the second applicant had committed against her own interests or the interests of others which would warrant divesting her of legal capacity.

X and Y v. Croatia, Application No. 5193/09, Judgment 03 November 2011.





Chapter 2: What is life like for people under guardianship?

During the negotiation process which led to the adoption of the UN Convention on the Rights of Persons with Disabilities a coalition of multi-level disabled people's organisations worked together to influence governments. It was called the International Disability Caucus, and MDAC was an associate member. To give a final push towards adoption, the Caucus developed an advocacy paper in 2006 calling for right to legal capacity for all:

"Imagine if someone else was making decisions for you. They could decide to take you away, lock you up, not listen to you, give you medication, block you from doing your work and living your life with your body and mind the way they are".8

This is not fiction. It is the reality for many people worldwide. Take Mr Shtukaturov, for example. He had been diagnosed with schizophrenia. On this basis a court deprived him of his legal capacity and placed him under the guardianship of his mother. He was not notified about these legal proceedings and only found out about the court decision by accident a year later. He tried to appeal the decision but it was rejected because, as a person under guardianship, he lacked legal standing to appeal. His mother placed him in a psychiatric hospital where he spent seven months. He objected to being there, and refused treatment but it was ignored and he received psychiatric medication against his will. During his time in the hospital he complained to the management about



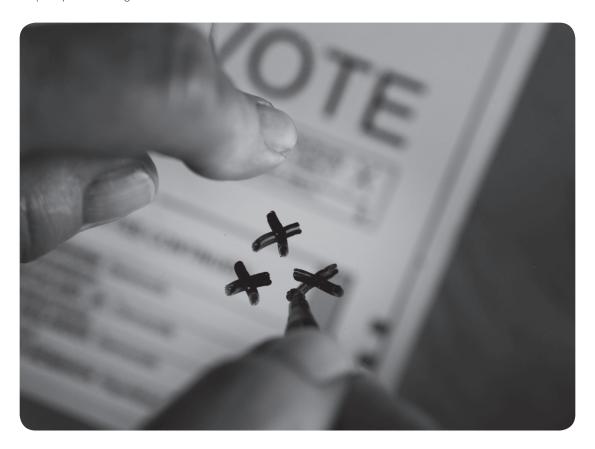
Pavel Shtukaturov @ Mental Disability Advocacy Center

⁸ International Disability Caucus: Advocacy paper during Ad Hoc Committee on a Comprehensive and Integral International Convention on and Promotion of the Rights and Dignity of Persons with Disabilities, Nothing about Us without Us, 31 January 2006.



not being allowed visits from his lawyer and his friends, not being allowed to go outside, having his personal belongings removed and the refusal of staff to provide him information about the reasons for his hospitalisation. MDAC helped him take his case to the European Court of Human Rights. In its judgment, the court found that guardianship constitutes a "very serious interference" with a person's private life and that mental illness should not automatically mean a person should be deprived of their liberty.⁹

The right to vote and to stand for elections is a basic human right which empowers citizens to take part in public life. A country can hardly call itself a democracy without guaranteeing this right its citizens. A man called Alajos Kiss had bipolar affective disorder and in 2005 he was placed under partial guardianship. A citizen of Hungary, he wanted to vote in the country's elections, but was not allowed as he was under guardianship. He took his case to the European Court of Human Rights, which said that he had suffered a violation of his rights. Political disenfranchisement further increases the political invisibility of people with disabilities and makes it easy for policy makers to ignore their demands.



⁹ More on the case of Shtukaturov v. Russia: http://mdac.info/sites/mdac.info/files/English_Shtukaturov_V_Russia.pdf. MDAC's senior legal monitor Dmitri Bartenev was counsel in this case, and MDAC developed the arguments. (last accessed: 8 Oct 2013).

¹⁰ Kiss v. Hungary, Application No. 38832/06, Judgment 20 May 2010. MDAC initiated this case.



There is a close link between the right live in the community¹¹ and the right to legal capacity. The European Court of Human Rights case of *Stanev v. Bulgaria*¹² illustrates this well.

Stanev v. Bulgaria

In 2000 Rusi Stanev was restricted of his legal capacity and was placed under partial guardianship. He was not informed of this. A year later, his guardian, a government bureaucrat whom he had never met, placed Mr Stanev into a social care institution in a remote mountain village 400km from his home. The director of the institution became his new guardian. The sanitary conditions were disgusting. There was a lack of heating and inadequate food. In 2002 the European Committee for Prevention of Torture told the government to shut the institution down. The government ignored them. Mr Stanev was forced to live in the institution for over eight years. He tried many times to leave, but, as the European Court found, "his desire to leave the home had been interpreted not as a freely expressed wish, but rather as a symptom of his mental illness". During that time he tried to remove himself from guardianship, but Bulgarian law does not allow the person under guardianship to do this: only the guardian (who wanted Mr Stanev under guardianship) could apply to the court, as could the prosecutor who showed no interest in helping Mr Stanev.



A 'bed' in the Pastra institution @ Amnesty International 2002

¹¹ Article 19 of the CRPD.

¹² Stanev v. Bulgaria, Application No. 36760/06, Judgment of the Grand Chamber of the European Court of Human Rights 17 January 2012.



In 2006 the Bulgarian justice system failed to help him, and so with the assistance of the Bulgarian Helsinki Committee and MDAC, he turned to the European Court of Human Rights. He had to wait six years for a judgment of that Court, but when – in January 2012 – the ruling was issued, Mr Stanev was not disappointed.

For the first time in its history, the Court found that the conditions of a social care institution amounted to 'degrading treatment' due to the grotesque conditions Mr Stanev had been forced to live in. Also for the first time, the Court found that Mr Stanev's detention in a social care institution amounted to unlawful detention. It also found that the fact that the law prohibited him from applying to have his guardianship removed was a breach of the right to a fair trial. "It seems clear to the Court", the judgment stated, "that if the applicant had not been deprived of legal capacity on account of his mental disorder, he would not have been deprived of his liberty." In other words, being under guardianship caused the other human rights violations which Mr Stanev was forced to suffer.

This ruling is significant for Bulgaria and for European countries with similar legislation. It places a direct obligation on the Bulgarian government to change the law. Despite promising to do so, the law remains unchanged, and Mr Stanev remains under guardianship. Despite him having left the deplorable institution, his right to live in the community has not been provided. MDAC continues to represent Mr Stanev in his struggle for equality and inclusion.



Rusi Stanev outside the European Court of Human Rights on 10 November 2009, after the hearing before the Grand Chamber in his case.

© MDAC



Forced hospitalisation, treatment without consent and denial of the right to access justice often go hand-in-hand with depriving a person of their legal capacity. In 2000, Mr Sýkora, from the Czech Republic, was deprived of his legal capacity without being given an opportunity to take part in the court proceedings. In 2005, following a dispute with his girlfriend, Mr Sýkora was taken to a psychiatric hospital on the basis of his mental illness and was treated against his will. As a result of the forced treatment his eyesight deteriorated. During his stay in hospital Mr Sýkora met lawyers working for the Czech NGO the League of Human Rights, which works with MDAC, in an attempt to challenge his detention and forced treatment. Yet Mr Sýkora's access to justice was blocked because, as a person under guardianship, he needed the permission of his guardian to challenge his detention. His guardian was the person who approved his detention in the first place. Eventually, the European Court of Human Rights found that restriction of Mr Sýkora's legal capacity was disproportionate. 13

The right to legal capacity affects even the most private domains of life, including the right to marry and have a family. In 2000, Mr Lashin was placed under total guardianship, the only available form of guardianship for people with disabilities in Russia. Two years later he and his fiancée decided to get married but it proved impossible for him, as people under guardianship in Russia are not allowed to marry. He could not accept this and tried to challenge the decision depriving him of his legal capacity. His fight was considered by Russian authorities and doctors as a sign of a "litigious personality" and as a result he was detained in a psychiatric hospital for a year. He was unable to challenge his detention because he was considered a voluntary patient, since his guardian – the hospital! – had volunteered its consent to him being hospitalised. When it examined his case, the European Court of Human Rights admonished Russian law, saying that the right to marry was one of many legal consequences associated with the restriction of his legal capacity. The Court held this interference in Mr Lashin's private life was disproportionate and in violation of his human rights.¹⁴

The drastic effects of restricting a person's legal capacity have been described in the following terms by the European Court of Human Rights:

"Divesting someone of legal capacity entails serious consequences. The person concerned is not able to take any legal action and is thus deprived of his or her independence in all legal spheres. Such persons are put in a situation where they depend on others to take decisions concerning various aspects of their private life, such as, for example, where to live or how to dispose of their assets and all income. Numerous rights of such persons are extinguished or restricted. For example, such person is not able to make a will, cannot be employed, and cannot marry or form any other relationship creating consequences for their legal status, etc." ¹⁵

¹³ Sýkora v. Czech Republic, Application No. 23419/07, Judgment 22 November 2012. MDAC, with the League of Human Rights, represented the applicant.

¹⁴ Lashin v. Russia, Application No. 33117/02, Judgment 22 January 2013. MDAC represented the applicant.

¹⁵ X and Y v. Croatia, Application No. 5193/09, Judgment 3 November 2011, para 90.



Chapter 3: A vision of equality and inclusion

A new approach (which is dull and ordinary)

The 2006 UN Convention on the Rights of Persons with Disabilities (CRPD) repatriates human rights to people who have had their rights taken away. It sets out that States should refrain from depriving anyone of their legal capacity. Instead, the CRPD demands that governments need to change their laws so that the legal capacity of people with disabilities remains intact, and that the State ensures they have access to supports to take part as full and active citizens, fully included within society.

Let's take Maria, an adult with mental health issues somewhere in Europe.

Under a guardianship model Maria is at risk of being placed under guardianship against her will. She may not even be informed about the legal proceedings leading to this. She may end up being treated in a psychiatric hospital without her consent, since her guardian can give consent to treatment on her behalf. Maria can be placed in a remote social care institution to live the rest of her life with six strangers in the same bedroom. Under guardianship she is not allowed to work, not allowed to leave the institution, and not allowed to choose when she goes to bed or what she has to eat or drink. She will be denied the right to have relationships with people she chooses, barred from voting and getting married, and will not be allowed to make a decision about whether she decides to have children. Under a guardianship system, Maria is regarded as an object for whom decisions need to be made.

Under a support model, Maria will be entitled to choose trusted friends to be her support network. The trusted friends around Maria will provide her support to understand financial, healthcare and other issues and would facilitate meetings between Maria and relevant professionals. The support network will help her describe the situations she faces, discuss the possible consequences of various options and support her to make informed choices about her life. Maria will be told about treatment options and alternatives. She will be able to live in the community choosing which community-based support services she needs, and will be able to work, to vote, and to form relationships which are meaningful for her. She will be able to have children and bring them up, with supports if needed. In a support system Maria is be regarded as a subject who can make her own choices.



UN Convention on the Rights of Persons with Disabilities (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
- 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- 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.
- 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.
- 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 of the CRPD was created in response to the historic and systemic denial of the right to legal capacity for many people with disabilities. Three systems result in the restriction of the legal capacity of individuals: status, outcome, and functional.

- The status approach denies a person's right to legal capacity based on their status as a person with a
 disability. An example of this is a system where the only evidence required for the imposition of a guardian
 is evidence of the individual's diagnosis of an intellectual disability. This is obviously inappropriate and
 unfair because it does not flow that one is incompetent to make any decisions simply based on a medical
 diagnosis.
- The **outcome approach** denies a person's right to legal capacity based on someone else's assessment that a decision, if left to the person with a disability, will result in a bad outcome. A situation where an individual refuses a medical intervention but the doctor overrides the refusal on the basis that they believe the treatment will have positive results is an example of this approach.



• The **functional approach** denies an individual's legal capacity on the basis of a test of a person's mental capacity. It often results in the partial removal of legal capacity for a person with a disability, generally including both a requirement of a 'mental impairment' as well as a test of whether the individual can understand the nature and consequences of the decision at hand. The CRPD Committee's draft general comment on Article 12 makes the point that many countries still unhelpfully conflate mental capacity with legal capacity.¹⁶

To the extent that these systems do not comply with the rights and duties described below, they are inconsistent with Article 12 of the CRPD.¹⁷ This is also the position that the CRPD Committee as indicated in its draft general comment on Article 12.

What are supports?

European and domestic laws should recognise that people with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. This is a basic requirement under Article 12(2) of the CRPD, and is reiterated clearly the CRPD Committee's draft general comment on Article 12. The starting point for law is to recognise legally independent decision-making. Laws should also acknowledge that some people with disabilities (and some people without disabilities) may need support to exercise their legal capacity. They may need assistance in understanding various options and communicating their decisions. This is set out in Article 12(3) of the CRPD.

The UN Committee on the Rights of Persons with Disabilities (CRPD Committee) has reviewed several States to assess how they are complying with their CRPD obligations. It has made clear that States must:

- take action to develop laws and policies to replace regimes of substitute decision-making with supported decision-making; and
- provide all relevant public officials, civil servants, judges, social workers and other stakeholders with training
 in consultation and cooperation with persons with disabilities and their representative organisations, at the
 national, regional and local levels. This should be on a human rights model of disability and recognition of
 the legal capacity of persons with disabilities and on mechanisms of supported decision-making.¹⁸

¹⁶ CRPD Committee, Draft General Comment on Article 12 of the Convention – Equal Recognition Before the Law, September 2013, available at: http://www.ohchr.org/Documents/HRBodies/CRPD/GC/DGCArticle12.doc (last accessed: 8 Oct 2013).

¹⁷ See Amita Dhanda, "Legal Capacity in the Disability Rights Convention: Stranglehold of the past or lodestar for the future?" Syracuse Journal of International Law and Commerce: 34, (2007), 429-462.

¹⁸ CRPD Committee, Concluding Observations on: Tunisia, para 23 (CRPD/C/TUN/CO/1); CRPD Committee, Concluding Observations: Spain, para 34 (CRPD/C/ESP/CO/1); Peru, para 25 (CRPD/C/PER/CO/1); Argentina, para 20 (CRPD/C/ARG/CO/1); China, para 22 (CRPD/C/CHN/CO/1); Hungary, para 26 (CRPD/C/HUN/CO/1); Paraguay, para 30 (CRPD/C/PRY/CO/1); and Austria, para 28 (CRPD/C/AUT/CO/1).



The CRPD Committee has also clarified that a system of supported decision-making includes the following:

- recognition of everyone's legal capacity and right to exercise it;
- accommodations (adjustments) and access to support where necessary to exercise legal capacity;
- regulations to ensure that support respects the person's will and preferences; including the establishment of feedback mechanisms to ensure that support is meeting the person's needs; and
- arrangements for the promotion and establishment of supported decision-making.

This means that governments should develop legislation that recognises the right to legal capacity of everyone with disabilities. The new structures must:

- · recognise that supported decision-making is built on relationships of trust;
- assign clear roles to supporters to provide information to help people with disabilities to make choices, and to assist them to communicate their choices to third parties (such as banks, doctors, employers, etc.); and
- prevent and remedy exploitation, violence and abuse, as detailed in Article 16 of the CRPD.

In summary, supported decision-making means that a person's legal capacity remains intact. So what does this mean in practice? Take Maria. ²⁰ It would mean that she should be provided with various supports which give primacy to her will and preference instead of depriving her of her legal capacity and placing her under the guardianship of someone. It would also mean that she could live in the community by deciding to use community-based support services instead of her guardian deciding to place her in an institution. It also means that she would be able vote for the candidate of her choice, using the assistance of a person of her choice instead of being excluded from political life, and so on.

Legal capacity law reform is possible. In February 2012 the Czech parliament adopted a new Civil Code. It abolishes plenary guardianship and introduces supported decision-making and other alternatives to guardianship. In November the same year, the parliament in Latvia passed a new law which similarly abolished plenary guardianship and introduced less restrictive alternatives. In July 2013 the Irish government published a draft law on assisted decision-making. These initiatives indicate that change can happen if there is political will, and in all three countries there has been very strong advocacy by civil society organisations.

¹⁹ CRPD Committee, Concluding Observations on: China, para 22 (CRPD/C/CHN/CO/1) and Austria, para 28 (CRPD/C/AUT/CO/1). In addition to this, the CRPD Committee has restated these requirements most recently in September 2013 in its Draft General Comment on Article 12 of the Convention – Equal Recognition Before the Law, available at: http://www.ohchr.org/Documents/HRBodies/CRPD/GC/DGCArticle12.doc (last accessed: 8 Oct 2013).

²⁰ See page 17, "A new approach (which is dull and ordinary)".





66 Eventually the folly of this will dawn on people and we shall all joyously realize that we are all abnormal, disabled, impaired, deformed and functionally limited, because, truth be told, that is what it means to be a human being.

Jerome E. Bickenbach²¹

Legal capacity facts and figures

Of the 28 Member States of the European Union, 25 have ratified the CRPD, as well as the European Union itself. Finland, Ireland and the Netherlands have signed but not yet ratified. Of the 47 Member States of the Council of Europe, 38 have ratified and seven have signed.²² Two Council of Europe Member States (Liechtenstein and Switzerland) have neither signed nor ratified the Convention. For a full analysis of how EU Member States handle legal capacity, see the July 2013 report of the European Union Agency for Fundamental Rights, referenced on page 7.

This report's geographical scope covers those countries where MDAC has worked on the right to legal capacity in recent years, namely Bulgaria, Croatia, Czech Republic, Hungary, Latvia, Lithuania, Moldova, Poland, Russia, Slovakia and Ukraine. In addition it also includes the jurisdictions of Albania, England and Wales, Northern Ireland, the Republic of Ireland and Spain, all of which are contemplating legal capacity law reform. This report does not attempt a statistical review. Many governments do not know how many people are under guardianship in their country.

Two findings are interesting.

The first interesting thing to note is that there is massive variance in the number of people under guardianship in different jurisdictions.²³ We can conclude that guardianship is applied indiscriminately. Many governments do not hold data on the number of people under guardianship. From the data which does exist, the numbers of people under guardianship varies drastically from country to country. Ireland has 48 people under the ward of court system (akin to guardianship) per 100,000 of the population, a low uptake which is not surprising given that the ancient ward of court system is so brutal. Bulgaria has 100 per 100,000 population under guardianship. In Latvia the figure is 106, Moldova 152, Poland 158²⁴, and Lithuania 167. The figure jumps in the Czech Republic

[&]quot;Minority Rights or Universal Participation: The Politics of Disablement" in M. Jones and L. A. Marks (eds.) Disability, Divers-Ability and Legal Change Martinus Nijhoff, 1999. 101-115.

²² Data available from http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en (last accessed: 08 Oct 2013).

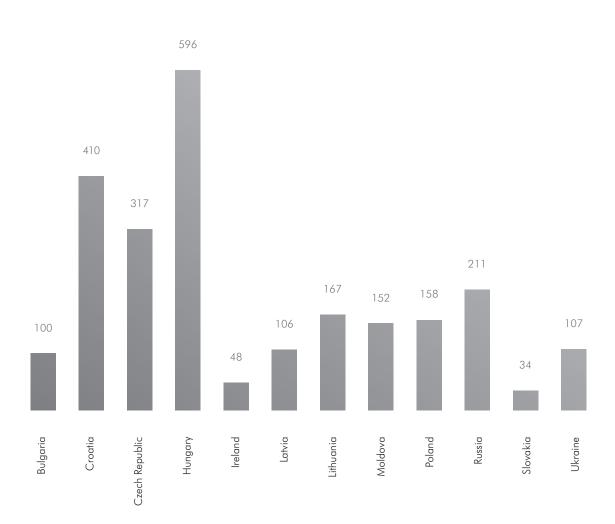
²³ This itself is a violation of Article 31 of the CRPD, which places an obligation on States to collect data to assist with implementation of the Convention.

²⁴ Figures are from 2008.



to 317 and in Croatia – the newest EU Member State – 410. At 596 per 100,000 population, Hungary is the European champion in heavyweight guardianship. This, coupled with the fact that the Hungarian government failed to make reforms when it had a chance last year, is not a title which any reasonable government would be proud to hold.

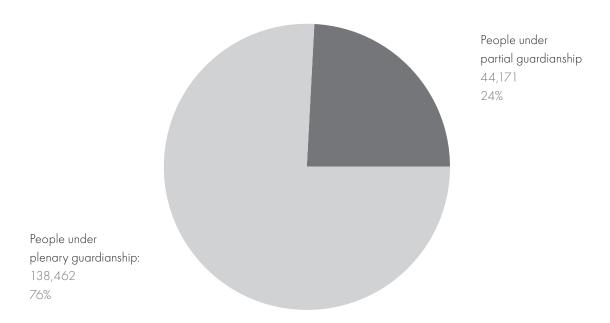
Rates per 100,000 of the population of people under guardianship, including plenary and partial guardianship





The second interesting thing about the data is related to partial guardianship. Many countries have systems of guardianship which affect all aspects of a person's life. These systems are called plenary, total, or full guardianship. A system which removes decision-making rights in certain areas (healthcare or finances, for example) is known as partial guardianship and is available for people with intellectual disabilities and people with psycho-social disabilities in several jurisdictions in Europe. Being under partial guardianship means different things in different countries. It can mean that the person concerned is completely prohibited from making decisions in certain areas of their life or that the person is authorised to make decisions only with the approval of the guardian in all or limited areas of their lives.

Total number and percentages of people under plenary guardianship compared with those under partial guardianship in Bulgaria, Croatia, Czech Republic, Hungary, Moldova, Slovakia and Poland





The percentage of people under plenary guardianship in those countries where partial guardianship also exists is 57% in Hungary, 59% in Moldova, 82% in the Czech Republic and 89% in Bulgaria and Croatia.²⁵

The aggregate data across central and eastern European countries which have both plenary and partial guardianship show that three quarters of people are under plenary guardianship. This is a surprising finding, given that partial guardianship is designed to offer a more tailor-made approach.

Total guardianship is preferred to partial guardianship because people other than those under guardianship consider it more cost-effective. It is cheaper to place someone under plenary guardianship because plenary guardianship court proceedings are shorter and because the judge need not go into details regarding different areas of life in which the legal capacity of the person concerned may be limited. Plenary guardianship is simply more convenient. Judges can go through more cases, pay less attention and deal with the matter more quickly. Plenary guardianship is an invitation for sloppy judging. Plenary guardianship is widely considered to be the best tool to protect third parties' interests and liabilities, such as banks, doctors, and of course guardians. As this report explains, these lousy justifications are on the wrong side of history, and they are based on myths. If a court procedure is cheap it does not mean that it is fair. An example of this is that plenary guardianship proceedings often lack adequate evidence; judgments are frequently based on a psychiatric opinion only. Protecting people with disabilities may be the intention, but under guardianship, protection becomes unjust interference in a person's right to make decisions about his/her life. As some of MDAC's cases demonstrate, even partial guardianship does not protect people from abuse or exploitation.

The CRPD calls on States to abandon guardianship and embrace a system which respects the "inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons". ²⁶ The next chapter sets out what governments should do.

²⁵ For sources of these statistics, see the country profiles in Chapter 7 of this report

²⁶ Article 3(a) of the CRPD.



Without legal capacity,
we are nonpersons in the eyes of the law
and our decisions have no legal force

Thomas Hammarberg²⁷

Chapter 4: The role of governments

Having examined supported decision-making demanded by Article 12 of the CRPD, this section looks more deeply at the actions which governments need to take in order to comply with Article 12 in reality.

To recap, Article 12 says that everyone has the right to:

- equal recognition as a person before the law;
- legal capacity
- on an equal basis with others
- in all aspects of life; and
- access to support to exercise legal capacity.

What could a new law look like? We will split the various elements into four parts.

1. Recognition of legal capacity on an equal basis in all areas of life

States must refrain from discriminatorily denying the legal capacity of people with disabilities. This requires law reform processes which assess all laws that relate to legal capacity to ensure that in their purpose and effect, they apply equally to all individuals and respect the full gamut of human rights norms.

In order to secure equal recognition before the law for people with disabilities, laws must recognise that persons with disabilities "enjoy legal capacity on an equal basis with others in all aspects of life" (CRPD Article 12(2)). This requires a system of 'universal legal capacity' – where all individuals' legal capacity is recognised, and where restrictions can only occur for a reason unrelated to disability. To accomplish this, States must abolish restrictions of legal capacity that are discriminatory on the basis of a disability or impairment, either in purpose or effect (CRPD Article 2). Status-based legal capacity systems violate Article 12 because they explicitly deny the legal capacity of people on the presence of a disability alone – for example, a law that allows a court to appoint a



guardian for someone just because that person has a particular diagnosis (e.g. dementia). Similarly, functional tests of mental capacity that lead to denials of legal capacity violate Article 12 if they are indirectly discriminatory, which in this sense means procedures that are disproportionately applied to people with disabilities.

MDAC recommends that States holistically examine all areas of law to ensure that people with disabilities do not have their right to legal capacity restricted on an unequal basis. Historically, people with disabilities have been denied their rights in many areas of their lives, including (but not limited to) consenting to or refusing sex, marriage, voting, founding and joining associations, contracting, consenting to or refusing medical treatment, testifying in a judicial procedure, being a juror, or agreeing or refusing to be detained and treated in a mental health facility.

2. Replace substituted decision-making with systems based on support

States must develop regimes of support for the exercise of legal capacity. States must also abolish regimes of substituted decision-making, otherwise this will persist even when alternatives exist.

The CRPD Committee has said on several occasions that Article 12 requires governments to replace substituted decision-making systems by systems of support.²⁸ Impermissible substituted decision-making are systems where (1) legal capacity is denied, (2) a substituted decision-maker is appointed by someone other than the individual, and (3) any decision made is bound by what is believed to be in the objective "best interests" of the individual – rather than respecting the individual's will and preference.

Article 12(3) of the CRPD establishes a State obligation to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." Like people without disabilities, some people with disabilities will need to be provided with informal supported decision-making frameworks and/or more formal support structures. Supported decision-making is not one model, but a cluster of innovations which vary greatly. These include specific support agreements with chosen support people, 29 receiving support from a community-based organisation, 30 or advance planning documents such as mental health advance directives, powers of attorney and so on. It is critical that these mechanisms include robust safeguards that protect the individual from exploitation, violence or abuse, and allow for modification if desired by the individual.

²⁸ CRPD Committee, Draft General Comment on Article 12 of the Convention – Equal Recognition Before the Law, para 46, September 2013, available at: http://www.ohchr.org/Documents/HRBodies/CRPD/GC/DGCArticle12.doc (last accessed: 8 Oct 2013). Importantly, the CRPD suggests not only a replacement of substitute decision-making systems, but their 'abolition'.

²⁹ See, for example, Canada, British Columbia, Representation Agreement Act, RSBC 1996, c. 405.

³⁰ Good examples include Swedish user-run services with Personal Ombudspeople (POs) for psychiatric patients, PO-Skåne – (www.po-skane.org) and Parasoll (www.parasoll.org).



A system based on supports will contain various methods which give primacy to a person's will and preference. It should provide protection both for rights related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live and so on) as well as rights related to freedom from abuse and ill-treatment (such as the right to life and right to bodily integrity). The law should contain provisions and safeguards, and must establish structures which:

- recognise the right to legal capacity;
- respect the will and preference of the individual;
- provide the opportunity to challenge and modify support arrangements;
- recognise that supported decision-making is built on relationships of trust;
- assign clear roles to supporters to provide information to help the person with a disability to make choices, and
 to assist the person to communicate these choices to third parties (such as banks, doctors, employers, etc.);
- accommodate for individuals who communicate unconventionally;
- prevent and remedy exploitation, violence and abuse, as outlined in Article 16 of the CRPD;
- carefully structure and monitor these provisions and safeguards to ensure that they do not over-regulate the lives of the individuals utilising them and become invasive and burdensome; and
- ensure that third parties give legal recognition to the role of support people and to decisions made with support.

Human rights are interconnected and interdependent, as Preamble paragraph (c) of the CRPD points out. The right to make one's own decisions and have those decisions respected can only be realised if there are meaningful options on offer. Currently, people with disabilities in many countries have very limited choices owing to the lack of community-based services in a number of jurisdictions (a requirement under Article 19 of the CRPD). States must work across government ministries to ensure that meaningful options are made available in the services and support offered to people with disabilities. This is where the government focal point established under Article 33(1) of the CPRD is useful.³¹

³¹ See "Building the Architecture for Change: Article 33 of the UN Convention on the Rights of Persons with Disabilities", Mental Disability Advocacy Center, 2011, available in several languages at www.mdac.info.



3. Recognise facilitated decision-making arrangements

In creating systems that respect the right to legal capacity, States must develop regulatory frameworks to address situations where, after all efforts are made, an individual's will or preference cannot be ascertained. We need to stress that the numbers of people for which facilitated decision-making is appropriate is very small. In these limited cases of last resort, there must be an option for facilitated decision-making, which is the appointment of an outside decision-maker. This structure must only apply when:

- supports have been exhausted (including creative communication techniques, building relationships, accessible information, etc.) and they have not lead to a decision; and
- the individual's will and preferences cannot be clearly and unambiguously ascertained, or there appears to
 be substantial conflict between preferences as contemporaneously expressed and the best understanding/
 interpretation of the person's long-term preferences; and
- the individual has not previously expressed his/her will or preferences (for example, in planning documents).

Facilitated decision-making is based on the protection of the rights, will and preferences of the individual. It should only be used for the minimum period of time which is necessary in the circumstances. Mechanisms must be available and meaningfully provided for the individual to make the transition to supported decision-making.

Facilitated decision-making is different from forms of impermissible substituted decision-making because in facilitated decision-making:

- legal capacity is not denied;
- decisions must be made giving primacy to the person's life narrative including any express or implied
 evidence of will and preferences;
- efforts must continue to be made to augment (strengthen) a person's residual decision-making abilities with a goal for them to transition to supported decision-making and independent decision-making; and
- the facilitator should develop a support network around the person with a view to developing communication with the person.

In order to prevent facilitated decision-making becoming the default option, States should be required to encourage everyone to express in advance their will and preferences with respect to key decisions, and to identify preferred supporters for the exercise of their legal capacity.



4. Begin the Law Reform Process

States must implement Article 12 of the CRPD immediately upon ratification. The right to equal recognition before the law is a civil and political right and therefore requires immediate realisation, rather than an economic, social or cultural right subject to progressive realisation.³²

In a law reform process that impacts on the lives of people with disabilities, States have obligations to "closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations" (Article 4(3) of the CRPD). When reforming legal capacity laws, States should involve people with disabilities in accordance with human rights law, but also achieve change that reflects the actual needs of the people whose lives will be affected. Support in decision-making is inherently dependent on cultural and social norms because it heavily relies on social interaction. In order to create laws that will meaningfully accord with these norms, people with disabilities and their representative organisations must be given the opportunity to play an active role in the construction of support systems that comply with the requirements of Article 12.

Recommendations to governments

The Mental Disability Advocacy Center calls upon policy-makers and legislators in all countries to:

- involve persons with intellectual disabilities and persons with psycho-social disabilities and their representative organisations in any law and policy reform process;
- develop laws and policies to replace regimes of substitute decision-making by supported decision-making;
- provide all relevant public officials, civil servants, judges, social workers and other stakeholders with training
 in consultation and cooperation with persons with disabilities and their representative organisations, at the
 national, regional and local levels, on the human rights model of disability and recognition of the legal
 capacity of persons with disabilities and on mechanisms of supported decision-making;
- initiate pilot projects to develop a wide variety of support measures, including supported decision-making;
- prevent and remedy exploitation, violence and abuse;
- collect comprehensive data on individuals subject to legal capacity restrictions and supports (including those subjected to guardianship and trusteeship while these systems exist).



Chapter 5: Overcoming law reform inertia

MDAC has been advocating for legal capacity law reform since its inception in 2002. We have taken many cases which have challenged abusive forms of guardianship. We have helped NGOs in many places, from Dublin to Moscow. Most of our work has been in central Europe and much of it in countries with stretched state budgets and fragile civil society organisations. In this section of the report MDAC shares some of the ways in which NGOs can call for legal capacity law reform.

Look across the statute book

Laws regulating the exercise of legal capacity may be found in laws such as comprehensive Civil Codes or in specific statutes such as the Mental Capacity Act (England and Wales). However, the right to legal capacity cuts across many other legislative domains. Election law, family law, inheritance law, social security law, medical law, mental health law, disability law, criminal law, banking law, and employment law are all areas which may well need to be examined for compliance with the UN Convention on the Rights of Persons with Disabilities (CRPD).

Strengthen the advocacy capacity of persons with disabilities

Even where non-governmental organisations of persons with disabilities exist, they are rarely involved in the development of legal capacity laws. Where civil society is meaningfully involved in law reform processes, government experts will be better informed. This creates a greater likelihood that laws will be implemented, bringing real change in the lives of people. For example, in the Czech Republic and Latvia (Bulgaria and Moldova are also on track), non-governmental organisations were invited to meaningful consultations on how to amend legal capacity legislation and these reforms are much more reflective of the requirements of the CRPD.

Report on stigma, abuse and neglect

It is not enough to modify and abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities: stigma, abuse and neglect should be also addressed in an effective way. Disability stereotypes reinforce negative attitudes in society which can result in discrimination. According to the Eurobarometer, although the proportion of Europeans who believe that discrimination on the grounds of disability is widespread has decreased since 2009, disability is still the second most widely perceived ground of discrimination in the EU.³³ Non-governmental organisations should identify forms of stigma and discrimination and make this information available for policy and decision-makers. NGOs also can play a role in documenting

European Commission, Special Eurobarometer 393: Discrimination in the EU – Summary, November 2012, available at: http://ec.europa.eu/public_opinion/archives/ebs/ebs_393_sum_en.pdf (last accessed: 8 Oct 2013).



abuses, issuing reports and recommending changes that tackle discrimination face on.

Dumping or adjusting?

During capacity-building events, conferences and round-table discussions, MDAC staff have spoken about the shift towards supported decision-making embodied in Article 12 of the CRPD. We spoke about the difference between a guardian and a support person, how to build a support network and how to put in place safeguarding mechanisms. The challenges of doing all of this are real and they exist in every country. Governments and civil society organisations alike are thirsty for information on how to go about adjusting the law, and what good systems actually look like in practice. International cooperation between governments³⁴ and also between civil society organisations is a way to learn about promising practices (and also very very bad practices!) For example, while the Czech Republic abolished plenary guardianship and introduced alternatives including supported decision-making, Latvia managed to abolish plenary guardianship, but failed to introduce supported decision-making. In the case of Hungary, plenary guardianship remained – renamed – in the law, and supported decision-making is now part of the legislation.

Lack of financial resources

All governments are short of resources. MDAC has repeatedly found a close link between legal capacity and segregation in institutions. We have conducted advocacy at domestic and international levels urging policy-makers to reallocate finances away from institutions and instead use the money on community-based supports. Moving from systems of substituted decision-making to ones based on support is primarily a human rights issue and therefore financial cost should not be decisive. In certain situations support may cost more than substitution but in other cases (for example where there is an existing support network around the person concerned), support is cheaper than substitution.



Getting politicians on board

Lack of political will has been a major obstacle for law reform in many of the countries where MDAC has worked. Without politicians willing to take action, there will be no law reform. If an issue is seen as unimportant or irrelevant, the status quo will remain. Politicians should be assisted to develop an understanding of the steps which should be taken in order to launch CRPD-compliant law reforms. If governments are slow to instigate law reform, civil society organisations can take cases against the government in courts, and if the State has ratified the Optional Protocol to the CRPD, a case could be developed for transmission to the CRPD Committee. MDAC has used the tool of strategic litigation in several domestic courts and at the European Court of Human Rights. This has resulted in recent legal capacity-related case victories including Lashin v. Russia, 35 Sýkora v. Czech Republic, 36 Kiss v. Hungary, 37 and Stanev v. Bulgaria. These are explained in the country snapshots, below.

Conclusion

Legal capacity law and policy reforms are on the agenda across Europe and in other regions around the world. States need to transform their systems. Civil society organisations can play a hugely important role in providing information, exposure to real people with disabilities, and expertise about how to involve people with disabilities in the law reform processes. This report and MDAC's "Legal Capacity Online" are contributions to the dearth of information in this vital area, and it is critical that people with disabilities themselves are at the heart of all reform processes.

³⁵ See www.mdac.info/en/23/01/2013/love-denied-european-court-tells-russia-to-allow-people-under-guardianship-to-marry (last accessed: 8 Oct 2013).

³⁶ See www.mdac.info/en/22/11/12/kafka-story-line-european-court-human-rights (last accessed: 8 Oct 2013).

³⁷ See www.mdac.info/en/european-court-human-rights-upholds-right-vote-per (last accessed: 8 Oct 2013).

³⁸ See www.mdac.info/en/stanev (last accessed: 8 Oct 2013).

³⁹ MDAC's Legal Capacity Online is a web-based guide for policy -makers, civil society organisations and people with disabilities on how substituted decision-making regimes should be replaced by systems of support. It is available at www.legalcapacity.org.



Chapter 6: The role of the European Union

The 2013 European Union Year of Citizens is drawing to a close. The year was dedicated to the rights that come with EU citizenship, including the right to equal recognition before the law.⁴⁰ In 2010 the EU ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). And, like any country, this creates obligations on the EU to ensure implementation. Unfortunately, the EU has to date taken insufficient substantial actions to ensure implementation of Article 12 of the Convention, claiming that it lacks legal competences to act.⁴¹ This section of the report outlines how this is not the case, and argues for action by EU institutions.

What does the European Union say about legal capacity?

In 2010 the EU adopted the European Disability Strategy 2010-2020.⁴² This document seeks "to empower people with disabilities so that they can enjoy their full rights, and benefit fully from participating in society and in the European economy, notably through the Single market."⁴³ In respect of the right to legal capacity, the Disability Strategy says 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 UN Convention."⁴⁴

Following the EU's ratification of the CRPD in 2010, it adopted a "Code of Conduct" which set out EU internal actions for implementation. The code, a technical document, is likely to be incomprehensible to most people. The reader may have reasonably expected this document to contain information about how the EU is going to implement each of the CRPD provisions, but it does not.⁴⁵ Instead, it separates the issues into areas of exclusive EU competence, areas of shared competence, and areas of supporting competence.

- 40 Guaranteed in the Charter of Fundamental Rights of the European Union (CFREU), Article 20.
- 41 Disability High Level Group (2009) 2nd Report on Implementation of the UN CRPD, European Commission.
- 42 European Commission: communication from the commission to the European Parliament, the council, the European economic and social committee and the committee of the regions "European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe"; European Commission Brussels, 15.11.2010 COM(2010) 636 final. Available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:EN:PDF (last accessed: 8 Oct 2013).
- 43 Ibid. para 2 (Objectives and Actions).
- 44 Ibid. para 2.1.3 (Equality).
- 45 European Union Declaration upon confirmation as a State Party to the CRPD, available at http://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec (last accessed: 8 Oct 2013).



EU jargon	What does the jargon mean?
'exclusive EU competence'	Member States cannot govern the issue, for example the European Union has an exclusive competence to accept obligations with respect to its own public administration. In this regard, the Community declares that it has power to deal with regulating the recruitment, conditions of service, remuneration, training etc. of non-elected officials.
'shared competence'	Member States and the EU both govern the issue, for example regarding action to combat discrimination on the ground of disability, free movement of goods, persons, services.
'supporting competence'	The EU can only intervene to carry out actions to support, coordinate or supplement the actions of Member States. It also means that the EU must not interfere with Member States in the exercise of these competences, for example in the area of protection and improvement of human health.

Why is the EU's approach faulty?

The EU's approach to legal capacity is rather minimal. Many EU treaties contain provisions relevant to the right to legal capacity, and may provide the EU with competene to act.⁴⁶

The EU's Disability Strategy 2010-2020 lists eight priority areas where the EU plans to take action. Legal capacity is only mentioned once in the strategy, in the part about equality. Yet legal capacity plays an important role in each of the eight areas, which are now taken in turn.

1. Accessibility

The EU Disability Strategy states that the Commission will "make goods and services accessible to people with disabilities and promote the market of assistive devices". ⁴⁷ The denial of legal capacity often makes it impossible to enter into a contract for goods and services by people who have had their legal capacity restricted, acting

⁴⁶ Article 2 of the Treaty on European Union (TEU) establishes that the EU is founded on the values of equality, respect for rights and the rule of law (Consolidated Version of the Treaty on European Union art. 2, 2010 O.J. C 83/01). The right to be equal before the law is in Article 20 of the Charter of Fundamental Rights of the European Union (CFREU).

⁴⁷ Stefanos Grammenos, IDEE Indicators of Disability Equality in Europe, ANED 2011 Task 4, Update and extend the piloting of quantitative implementation indicators. Comparative data on a selection of quantitative implementation indicators. October 2011. Para 0.3. Available at: http://www.disability-europe.net/content/aned/media/ANED%202011%20Task%204%20-%20 Synthesis%20Report.doc (last accessed: 8 Oct 2013).



as a complete barrier. A person under guardianship is, in most EU countries, prohibited from opening or using a bank account, or signing a contract for other goods and services, such as a mobile phone. In addition to this, accessibility of goods and services can facilitate the independence of persons with disabilities. Yet, independence is meaningless without autonomy and the exercise of the right to legal capacity. The EU should be making sure that every adult in Member States can access goods and services.

2. Participation

The EU Disability Strategy states that the Commission will "ensure that people with disabilities enjoy all benefits of EU citizenship; remove barriers to equal participation in public life and leisure activities; promote the provision of quality community-based services". ⁴⁸ The benefits of EU citizenship are out of reach for people deprived of their legal capacity. In many EU countries, the right of equal citizenship of persons with disabilities is automatically denied when their legal capacity is restricted: they are denied the right to participate in public life, denied the right to vote in local, national and European parliamentary elections, ⁴⁹ and denied the right to associate through forming or joining non-governmental organisations. ⁵⁰

Citizenship is a shared competence between the EU and its Member States.⁵¹ The European Commission should be taking steps to work with Member States to ensure that people under guardianship are not prohibited from exercising their right to vote.⁵² It is a glaring loophole that people under guardianship in many countries are prohibited from voting in European Parliamentary elections. Having acceded to the CRPD, the EU should be taking a proactive approach to ensure full compliance with Article 29 of the Convention which sets out the right to vote and stand for election for all people with disabilities.

Participation means much more than citizenship in the legal sense. It also covers, for example, consumer protection where the EU has clear competencies to act.⁵³ By setting up common rules and standards the EU contributes to

- 48 Ibid.
- 49 EU Fundamental Rights Agency (FRA), The right to political participation of persons with mental health problems and persons with intellectual disabilities, October 2010, FRA (2010).
- 50 Ibid.
- TFEU Article 4(2)(j); The right to vote of EU citizens has been established by both the Treaty on the Functioning of the European Union (Article 20 and 22 TFEU) and the Charter of Fundamental Rights of the European Union (Article 39 and 40 CFREU).
- 52 The Council may take recourse to a special legislative procedure (Article 22(1) TFEU).
- 53 See, for example, Article 169 TFEU; Directive 2011/83/EU of the European Parliament and of the Council of 25 October 2011 on consumer rights, amending Council Directive 93/13/EEC and Directive 1999/44/EC of the European Parliament and of the Council and repealing Council Directive 85/577/EEC and Directive 97/7/EC of the European Parliament and of the Council Text with EEA relevance. Available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:304:0064:01:EN:HTML (last accessed: 8 Oct 2013).



the proper functioning of the internal market.⁵⁴ Consumer protection is relevant for example regarding contracts for supply of water, gas, electricity or district heating.⁵⁵ In order to promote the interests of consumers, the EU also contributes to protecting the health and safety of consumers as well as promoting their right to information and education, etc.⁵⁶ However, if an adult person is placed under guardianship, she is denied the right to enter into legal relationships, meaning that she is not considered as a 'consumer'. It follows that people placed under guardianship are denied the enjoyment of consumer protection mechanisms of the EU. The institutions of the EU should act in order to recognise that all people with disabilities are entitled to consumer protection under EU law and practice, alongside all other citizens.

3. Equality

The EU Disability Strategy states that the Commission will "combat discrimination based on disability and promote equal opportunities".⁵⁷ The EU has committed to support and supplement Member States efforts to develop legal capacity laws that conform to norms required by the CRPD.⁵⁸

In addition to the EU's power to combat discrimination,⁵⁹ the European Commission should reignite its efforts to propose an anti-discrimination directive.⁶⁰ Such a directive may well be necessary for the EU to comply with Article 5 of the CRPD which sets out the right to non-discrimination in all areas of life, and also Article 12 of the CRPD which calls for equal recognition before the law. Equal recognition before the law is set out in the Charter of Fundamental Rights.⁶¹ The Commission should interpret the Charter in light of the CRPD, which requires incorporating the obligation for Member States to provide supports for people to exercise their legal capacity.

In replacing substituted decision-making regimes with supported decision-making regimes, primary competence appears to lie with the Member States. However, the EU has an important role to play in supporting them to coordinate actions in this area – as is clear in the EU Disability Strategy for 2010-2020.

- 54 See Article 1 of Directive 2011/83/EU of the European Parliament and of the Council of 25 October 2011 on consumer rights, amending Council Directive 93/13/EEC and Directive 1999/44/EC of the European Parliament and of the Council and repealing Council Directive 85/577/EEC and Directive 97/7/EC of the European Parliament and of the Council Text with EEA relevance. Available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:304:0064:01:EN:HTML (last accessed: 08 Oct 2013).
- 55 Ibid. Article 3.
- 56 See Article 169(1) TFEU.
- 57 Stefanos Grammenos, IDEE Indicators of Disability Equality in Europe, ANED 2011 Task 4, supra note 47.
- 58 European Disability Strategy 2010-2020, supra note 42.
- 59 The EU has a mandate to combat discrimination based on disability (Article 10, TFEU) and to take action accordingly within the limits of its powers (Article 19, TFEU).
- 60 Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation," European Commission (2008), available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52008PC0426:en:NOT (last accessed: 08 Oct 2013).
- 61 Article 20, CFREU.



4. Employment

The EU Disability Strategy states that the Commission will "raise significantly the share of persons with disabilities working in the open labour market". ⁶² Thousands of people with disabilities who have had their legal capacity denied in EU Member States are prohibited from signing an employment contract. They are thereby excluded from the labour market completely or forced to work outside it, meaning that they are likely to be exploited and under-paid. Barring someone from working creates a serious barrier to living independently and earning a livelihood. There is a bidirectional link between disability and poverty and denying a person with a disability the right to work will only exacerbate their poverty. ⁶³

The European Commission should take measures to ensure that persons with disabilities are not excluded – through legal capacity laws at a minimum – from being included in the labour market.⁶⁴ The European Commission should also support and complement the activities of Member States in ensuring that everyone with disabilities is lawfully enabled to enter into, and be supported in, the open labour market.⁶⁵

5. Education and training

The EU Disability Strategy states that the Commission will "promote inclusive education and lifelong learning for students and pupils with disabilities". 66 Education and training is essential for providing an individual with the skills necessary for life, and for taking decisions throughout their life (in particular through exercising their legal capacity). Education provides children with the tools they need to participate in society. The EU could incorporate the idea of supported decision-making, including building circles support for persons with disabilities, in its promotion of the right to inclusive education.

6. Social protection

The EU Disability Strategy states that the Commission will "promote decent living conditions, combat poverty and social exclusion".⁶⁷ Legal capacity is essential for each of these areas. Promoting decent living conditions should include the freedom to choose a place of residence on an equal basis with others. People who have

- 62 Stefanos Grammenos, IDEE Indicators of Disability Equality in Europe, ANED 2011 Task 4, supra note 47.
- 63 International Labor Organization: Disability and Poverty Reduction Strategies How to ensure that access of persons with disabilities to decent and productive work is part of the PRSP process. November 2002, available at: http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_107921.pdf (last accessed: 08 Oct 2013).
- Article 153(2)(b), TEFU. The European Commission should also push for the removal of laws that deprive people with disabilities of the legal capacity to enter into employment contracts because it is the only way to secure full transposition of Directive 2000/78/EC.
- 65 Article 153(1)(h) and (j), TEFU.
- 66 Stefanos Grammenos, IDEE Indicators of Disability Equality in Europe, ANED 2011 Task 4, supra note 47.
- 67 Ibid.



been denied their legal capacity are often prohibited from making decisions about where they live.⁶⁸ They are also frequently prevented from controlling their finances and, as noted above, from entering into employment contracts. All of these factors substantially increase the risk of poverty. Finally, when a person is denied their legal capacity, she is basically in the state of 'civil death'. This actually leads to marginalisation and even to exclusion of the person concerned from society. The EU is encouraged to incorporate these issues into its work on promoting social protection.

7. Health

The EU Disability Strategy states that the Commission will "promote equal access to health services and related facilities".⁶⁹ Often, a person denied legal capacity is not permitted to make decisions about their own medical treatment. The guardian is legally entitled to provide consent or refusal to treatment on behalf of a person with disabilities. This creates unequal access to health services and facilities because the person under guardianship is at the whim of their guardian. In promoting the right to health, the European Commission should consider issues of consent, including the right of individuals to choose, or reject, healthcare interventions and services.

8. External action

The EU Disability Strategy states that the Commission will "promote the rights of people with disabilities in the EU enlargement and international development programmes". To It is essential that all EU enlargement funds are used towards programs that foster the recognition of the right to legal capacity. They must not be used on programs such as the building and/or maintenance of institutions, which further regimes of substituted decision-making and the denial of legal capacity.

The EU Disability High Level Group (DHLG) is a body which is composed of one representative of each Member State of the EU. The DHLG was established to monitor the latest policies and priorities of Governments with regard to people with disabilities, and to advise the European Commission on methods for reporting in future on the EU-wide situation concerning disability. In its first annual report in 2008, the DHLG lists legal capacity as a key challenge of implementing the CRPD and attempted to share good practice in this regard. The report notes that in some Member States legal capacity is restricted through guardianship, and that the CRPD requires this approach to change to a support-based system. It concludes that "(t)his is a complex area of law and requires consultation and reflection". The report notes are consultation and reflection.

- 68 See Article 19(a), CRPD.
- 69 Stefanos Grammenos, IDEE Indicators of Disability Equality in Europe, supra note 47.
- 70 Ibid.
- 71 More information on DHLG is available at http://ec.europa.eu/employment_social/soc-prot/disable/hlg_en.htm (last accessed: 08 Oct 2013).
- Disability High Level Group (2008) First Report on Implementation of the UN Convention on the Rights of Persons with Disabilities, European Commission, p. 35.



The DHLG's second annual report, published in 2009, purports to set out achievements and challenges in legal capacity in each of the Member States.⁷³ Although this information is helpful, the report suffers from three significant weaknesses. First, the information is self-reported by governments and there is no process of verification. Second, the information is in different formats for each Member State, so some aspects of Article 12 are set out for one State but not another. Third, there is no summary or analysis, making it very difficult to compare across Member States or to pick out promising practice.

It then seems that DHLG forgot about legal capacity. The subject is barely mentioned in the 2010, 2011 or 2012 annual reports, ⁷⁴ rendering comparison over time impossible at the European level. The omission casts significant doubt on the DHLG's commitment (and indeed that of the Commission, which convenes the DHLG) to implementing their 2008 declaration that legal capacity constitutes one of the "challenges that should be considered by each key player involved in the implementation of the UN Convention". ⁷⁵

Denying someone their autonomy is clearly of concern to the people affected. The widespread denial of legal capacity of persons with disabilities should be of clear concern to the European Commission. The centrality of the right to legal capacity to the enjoyment of all rights and entitlements, including those conferred by EU citizenship, was acknowledged by the EU Agency for Fundamental Rights in its 2010 report on participation in political life of people with disabilities. However, the European Commission has taken little action to work towards the realisation of this fundamental right. The Commission should use its power, within the framework of its competences, to guarantee the right of everyone within the EU to equal recognition before the law.

⁷³ Disability High Level Group (2009) Second Report on Implementation of the UN Convention on the Rights of Persons with Disabilities, European Commission.

⁷⁴ Disability High Level Group (2010) Third Report on Implementation of the UN Convention on the Rights of Persons with Disabilities, European Commission; Disability High Level Group (2011) Fourth Report on Implementation of the UN Convention on the Rights of Persons with Disabilities, European Commission; Disability High Level Group (2012) Fifth Report on Implementation of the UN Convention on the Rights of Persons with Disabilities, European Commission.

⁷⁵ Disability High Level Group (2008), supra note 72, p. 35.

⁷⁶ FRA (2010) supra note 5.



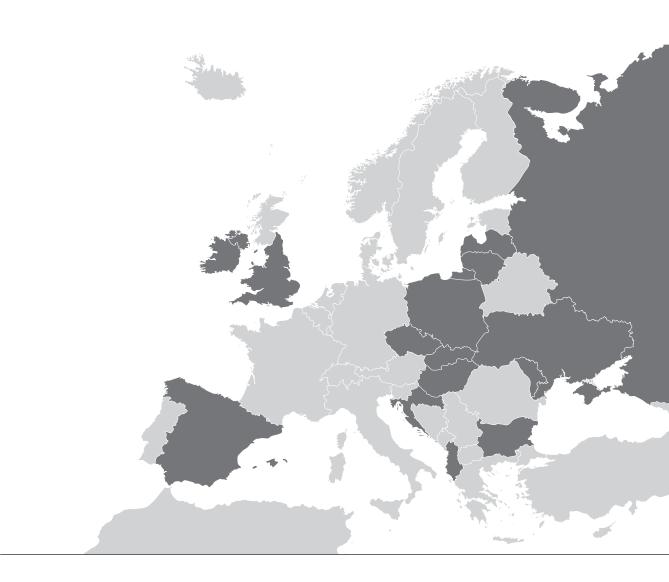
Recommendations to the European Union

While governments play a key role in implementing Article 12 of the CRPD at domestic level, the European Commission must proactively act at the European level. As such, MDAC calls upon the European Commission to:

- facilitate the abolition of systems which deprive people with disabilities of their legal capacity, ensuring that all can have equal access to goods and services;
- recognise that all adults with disabilities have legal capacity and are citizens of the European Union and are thus entitled to exercise their right to vote and stand for election in European and municipal elections;
- facilitate a common approach and provide guidance in order that Member States interpret Article 12 of the CRPD in a coherent way and in line with the jurisprudence of the CRPD Committee;
- ensure that laws that deprive people with disabilities of the legal capacity to enter into employment contracts are removed, in order to facilitate full implementation of Council Directive 2000/78/EC;
- promote circles of support and supported decision-making processes when encouraging Member States to implement inclusive education for children with disabilities;
- ensure that funds are not used for programs that perpetuate violations of Article 12 such as institutionalisation
 of people with disabilities, but instead are used on programmes which recognise and promote the legal
 capacity of people with disabilities;
- ensure that comprehensive and comparable data is collected across Member States on forms of guardianship, including statistics, upon which technical assistance can be provided to ensure implementation of Article 12.



Chapter 7: Country snapshots





Albania

Population
People under guardianship
From which under plenary
From which under partial
Date of CRPD ratification

3,011,405⁷⁷ No data available No data available No data available 15 Nov 2012⁷⁸



- Population figures for all countries are from CIA's The World Factbook https://www.cia.gov/library/publications/the-world-factbook/ (last accessed: 8 October 2013).
- 78 For a list of countries which have signed and ratified the CRPD, see http://treaties.un.org/Pages/ViewDetails. aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en (last accessed: 8 Oct 2013).



People with mental disabilities not protected

"The person whose rights are being removed," is the phrase that Article 307 of the Albanian Family Code uses to aptly describe the current situation of persons with disabilities. This provision poignantly summarises the way in which Albanian legislation – and policy – fails to comply with the requirements of the CRPD.⁷⁹

The capacity to act in Albanian legislation refers to the ability to perform legal acts, to bear rights and to undertake obligations. Full capacity to act is gained when a person becomes 18 years old. The legal capacity to act is a quality of the subject and not a right. It enables the individual, through their actions, to gain rights. Albanian legislation separates people into three groups:

- Persons with full legal capacity to act;
- Persons with partial capacity to act;
- Persons deprived of the legal capacity to act.

Under the Code of Civil Procedure a request for removal or restriction of a person's capacity to act can be made by a spouse, family members and persons who have a 'legitimate interest'. A court decides on the request for removal or limitation of the ability to act after asking the person, hearing people from their family or neighbourhood, as well as on the opinion of a doctor or other experts.⁸⁰

Until now, no steps have been undertaken to realise fulfilment of Article 12 of the CRPD. It is worth mentioning that people with intellectual disabilities, and people with psycho-social (mental health) disabilities experience substantial levels of discrimination in society, and do not receive the same level of protection as people from other protected groups, including those who are partially-sighted, blind, and those with other physical disabilities. This excludes many persons with disabilities. They are generally treated by other social laws and their benefits from such schemes are much lower.

It is vital that the European Union engages with the country under the European Neighbourhood Policy in order to promote full CRPD implementation.

⁷⁹ United Nations Albania, Progress Report, UNDP Albania, 2012, available online at: http://www.al.undp.org/content/dam/albania/docs/misc/2012_UN_Progress_Report.pdf (last accessed: 8 Oct 2013).

⁸⁰ Code of Civil Procedure, article 382.



Bulgaria

Population 7,037,935
People under guardianship 7,040⁸¹
From which under plenary 6,249
From which under partial 791

Date of CRPD ratification 22 Mar 2012



Data used in the "Draft Concept Note for changes in national legislation relating to the standards of Article 12 of the UN Convention on the Rights of Persons with Disabilities" which was published on the website of the Bulgarian Ministry of Justice on 10 November 2012 (page 3), available at: http://pris.government.bg/prin/document_view.aspx?DocumentID=8RMxcMeAentEcHr /4hQgUw== (last accessed: 8 Oct 2013).



On the road towards abolishing plenary guardianship and introducing supported decision-making

Bulgaria ratified the CRPD in January 2012. Nine days previously, the European Court of Human Rights delivered its judgment in the case of *Stanev v. Bulgaria*, ⁸² in which the applicant was represented by the Bulgarian Helsinki Committee and MDAC. In March 2012 the Ministry of Justice established a working group to prepare a new legal capacity law. The same month MDAC co-organised a two-day seminar for the newly-established working group. Their concept note was presented to the government in September, at a conference where NGO representatives, persons with disabilities and governmental bodies were present. In November, the Council of Ministers adopted the concept note.

According to the concept note (a) plenary guardianship will no longer exist in the new legislation; (b) there will be no automatic loss of rights if somebody is placed under trusteeship, which is equal to partial guardianship; (c) supported decision-making shall be enshrined in law; and (d) advance directives and enduring powers of attorney are to be introduced as alternatives to guardianship.

The concept note lists several principles which should be considered when applying the above measures: (a) necessity and adequacy; (b) respect for the will, preferences and values of the person; (c) proportionality; (d) periodic review; (e) avoidance of conflicts of interest and unlawful influence; and (f) flexibility. When deciding on the applicable measure, the person's situation needs to be assessed in order to identify whether they can make their own choices independently and whether they can express decisions made.

The concept note points out that court proceedings regarding placing a persons under trusteeship must now include the following: (a) An obligatory hearing involving the person concerned without any exceptions; (b) Obligatory involvement of multidisciplinary experts including from the fields of psychiatry/psychology, an expert on communication who knows the person concerned, a doctor or a social worker who is in a relationship of trust with the person concerned, and a person who knows the person concerned very well; (c) Duty on the court to make efforts to find a trustee with whom the person concerned is in a relationship of trust; and (d) A time period of maximum three years after which there will be a statutory review.

A new working group is drafting the legal text and MDAC is represented in this working group. In October 2012 the Bulgarian Centre for Not-for-Profit Law (BCNL), along with other organisations, launched a pilot project on supported decision-making.



Croatia

Population 4,480,043
People under guardianship 18,382⁸³
From which under plenary 16,355
From which under partial 2,027

Date of CRPD ratification 15 Aug 2007



B3 Data was used in a Joint submission of the Mental Health Europe and The SHINE – Association for Social Affirmation of People with Psychosocial Disabilities regarding the case of *X and Y v. Croatia* to the Department for the Execution of Judgments of the ECHR, Council of Europe. 28 November 2012.



Revision of legal capacity laws behind closed doors

Legal capacity of people with disabilities can be fully deprived or partially restricted in Croatia if the adult, "on account of mental illness or other reasons, is unable to care for his or her own needs, rights and interests, or represents a risk to the rights and interests of others".⁸⁴

In December 2012 Croatia lifted the exclusion of people under guardianship from exercising their right to vote. ⁸⁵ However, people under full guardianship are still deprived of their right to decide where and with whom to live, the right to marry, to exercise parental rights and so on. There is no statutory review of the necessity of guardianship. A court decision depriving someone of their legal capacity may not to be served on the person concerned if "he or she cannot understand the legal consequences of that decision or where it would be detrimental to his or her health". ⁸⁶ MDAC analysed the Croatian law in detail in a 2011 report. ⁸⁷

In its report to the CRPD Committee, the Croatian government referenced a working group on law reform. ⁸⁸ In May 2013 the Ministry of Social Policy and Youth launched public discussion on a draft Family Act, in which it is planned to: abolish plenary guardianship; establish a system of statutory reviews in relation to restriction of people's legal capacity and guardianship placements; and provide people with disabilities the right to challenge decisions on restriction of their legal capacity and on the appointment of a guardian.

Since the planned changes are not in line with the CRPD, in June 2013 MDAC sent a letter pointing this out to the Minister of Social Policy and Youth.

Excerpts from interviews - Vojnić Institution

In 2010-11 MDAC and a Croatian psycho-social disability NGO called SHINE, visited several Croatian institutions including Vojnić. This is a private psychiatric hospital where the majority of patients have dual diagnoses of intellectual disability and psycho-social disability.

"A guardian's rights are greater than their obligations." (Director of Vojnić)

"Decisions concerning residents are easier to take if we do not have to consult and seek consent from the residents themselves or their family." (Staff member of Vojnić)⁸⁹

- 84 Section 159(1) of the Family Act.
- 85 See http://www.mdac.info/en/14/12/2012/croatia-lifts-voting-prohibition-for-people-with-disabilities (last accessed: 8 Oct 2013).
- 86 Section 329(2) of the Family Act.
- 87 "Out of Sight: Human Rights in Psychiatric Hospitals and Social Care Institutions in Croatia"., Mental Disability Advocacy Center, 2011. Available from www.mdac.info. (last accessed: 8 Oct 2013).
- 88 Initial report of Croatia to the UN Committee on the Rights of Persons with Disabilities (CRPD/C/HRV/1), para 59, available at: http://www2.ohchr.org/SPdocs/CRPD/futuresession/CRPD.C.HRV.1_en.doc (last accessed: 8 Oct 2013).
- 89 "Out of Sight" report, op cit, pp 49 and 57.



Czech Republic

Population 10,177,300
People under guardianship 32,261⁹⁰
From which under plenary 26,520
From which under partial 5,741

Date of CRPD ratification 28 Sep 2009



Data used in the Alternative Report for the UN Committee on the Rights of Persons with Disabilities – Czech Republic, November 2011, submitted by the National Disability Council and other NGOs, including LIGA and MDAC, p. 17.



New law abolishes plenary guardianship and introduces supported decision-making from 2014

As a result of a seven-year campaign by civil society, including MDAC, a new Civil Code was passed in the Czech Republic in February 2012.⁹¹ It abolishes plenary guardianship and introduces supported decision-making which is built around the following principles: (a) legal capacity of people with disabilities remains intact; (b) support persons bind themselves by contract to support the person concerned; (c) the contract needs to be approved by court; and (d) the role of the support person is to assist the supported person by facilitating information sharing, communication and to help with providing advice for the person concerned.

The new Civil Code introduces advance directives so that a person "who foresees his or her own legal incapacity can express his or her will so that his or her affairs are conducted in a prescribed manner or by a designated person, or that a designated person becomes his or her guardian." Another new measure is "representation by next of kin." This means that if an impairment prevents an adult from performing legal acts on their own and if this person has no other representative, he or she can be represented by his or her close relatives. In this case, the legal capacity of the person remains intact. Representation refers to everyday affairs including managing daily finances. The representative is not allowed to give proxy consent to healthcare interventions or interventions having a permanent impact on the mental or physical integrity of the person.

The new Civil Code introduces the institution of guardianship councils. These may be set up for each person under guardianship – unfortunately they are not mandatory. They will be responsible for monitoring the activities of guardians and will be composed of at least three members, and the guardian cannot be a member. The guardianship council is required to meet at least once a year.

The new law allows for the restriction of legal capacity as a last resort, but in doing so it introduces several new safeguards, such as time-limits. One of the main sources for the legal reform was the UN Convention on the Rights of Persons with Disabilities (CRPD), which was ratified by the Czech Republic in 2009. Although the new legislation does not, in MDAC's view, fully comply with the CRPD, it is a step towards full recognition of legal capacity for all. The legislation comes into force in January 2014.



Sýkora v. Czech Republic

In 2000, Mr Sýkora was deprived of his legal capacity without being summoned to the court. Mr Sýkora was represented by an employee of the court who had never met him, and did not participate at the hearing. Furthermore, the decision of the court was not served on him. In 2005, following a verbal, non-violent dispute with his partner, Mr Sýkora was taken to a psychiatric hospital where he was treated against his will. As a result of the forced treatment, his eyesight deteriorated. Even though Mr Sýkora wanted to challenge his detention in the psychiatric hospital, he was denied the right to initiate proceedings since his guardian consented to the detention.

"The Court takes note of the applicant's contention that the measure applied to him had not been lawful and did not pursue any legitimate aim. However, in its opinion, it is not necessary to examine these aspects of the case, since the decision to remove legal capacity from the applicant was in any event disproportionate to the legitimate aim invoked by the Government" (para 104 of the judgment).

European Court of Human Rights, Application No. 23419/07, Judgment 22 November 2012.



England and Wales

Population 56,170,900

Number of deputyships in 2013 53,234⁹²

Deputyships granted in 2010 9,543⁹³

For property and affairs 9,437⁹⁴

For welfare matters 106⁹⁵

Date of CRPD ratification 8 June 2009

- 92 Information obtained under the Freedom of Information Act 2000 on 11 April 2013, letter on file at MDAC.
- 93 Ibid.
- 94 Court of Protection Report 2010, Judiciary of England and Wales, p. 25.
- 95 Ibid.



Deprivation of legal capacity still allowed

The Mental Capacity Act 2005 (MCA)⁹⁶ and the Mental Health Act 2007 (MHA)⁹⁷ are key pieces of legislation in England and Wales that allow for the deprivation of legal capacity. The MHA allows for forced detention and psychiatric treatment and the appointment of guardians.⁹⁸ The MCA allows for 'deputies' to be appointed for welfare and/or property matters, and in respect of detention in hospitals or care homes, under a section entitled 'deprivation of liberty safeguards'. It also gives wide scope for professionals to determine whether an individual lacks functional mental 'capacity'. Once decided, the professional can deprive the individual of their legal capacity and make decisions on their behalf using a 'best interests' standard that does not prioritise the will and preference of the individual,⁹⁹ in violation of Article 12. MDAC has participated in several events in England and Wales focused on increasing awareness of Article 12 of the CRPD and attempting to further the discussion on how the English and Welsh legislation may need to be reformed to come into compliance with human rights standards.

'Alan's' case¹⁰⁰

Alan and Kieron had lived together in local authority accommodation and had begun a sexual relationship. Alan was aged 41 years old and described as having a 'moderate' learning disability, and as being sociable and able. The local authority requested that the Court of Protection consider whether he had the 'mental capacity' to consent to sexual relations, and if he did not to authorise a restriction on contact between him and Kieron. Alan had since been moved to another placement, where he was closely supervised to prevent further sexual activity, a regime which constituted a deprivation of his right to liberty. When asked how he would feel if he was allowed to resume sexual activity with Kieron, he said 'it would make me feel happy' and 'I want to kiss them again'.

⁹⁶ England and Wales Mental Capacity Act 2005, c. 9.

⁹⁷ England and Wales Mental Health Act 2007, c. 12.

⁹⁸ Guardians under the MHA have only three 'essential powers': to decide where a person lives, to require them to attend training, education or medical appointments, and to require access be granted to them for medical or other persons. Guardians under the MHA have no authority to make decisions about a person's property and affairs, medical treatment, relationships etc. The MCA must be used for authority in these areas.

⁹⁹ For a discussion of the role of the individual's will and preferences in 'best interests' decisions, see: ITW v Z & Ors (2009) EWHC 2525 (Fam).

¹⁰⁰ D Borough Council v AB (2011) EWHC 101 (COP), available at: http://www.bailii.org/ew/cases/EWHC/COP/2011/101.html (last accessed: 8 Oct 2013).



The court found that in order to demonstrate the mental capacity to consent to sex, a person must understand: 'the mechanics of the act', that there are health risks involved and that sex between a man and woman may result in the woman becoming pregnant (although the judge doubted that the latter requirement was relevant to sex between people of the same gender as in this case). The court found that Alan did not understand the health risks and accordingly declared that he lacked the capacity to consent to sex and that the regime of supervision for the prevention of sexual activity was in his best interests. The court did, however, declare that the local authority should provide Alan with sex education 'in the hope that he thereby gains that capacity'.

E's case¹⁰¹

Ms E was a 32 year old woman with severe anorexia nervosa, which she had developed in her early teens and for which she had undergone compulsory detention and treatment on many occasions under the MHA. Her health was presently in a critical state, and without treatment she would certainly die. However, she felt that 'She has tried to explore every avenue to get over her demons but has failed. She wants to live for the remainder of her life as she chooses, and if necessary to be allowed die with dignity.' Accordingly, she made two 'advance decisions' refusing treatment, including force feeding or any medical intervention which would prolong her life. The court was asked to determine their validity, including – retrospectively – determining whether or not she had the 'mental capacity' to make the advance decisions.

The court heard evidence from E's parents, who supported her in her wishes. A medical expert expressed the view that 'anyone with severe anorexia would lack capacity to make such a decision'. The Court held that against the 'alerting background' of E being detained under the MHA shortly after making the advance decision, it was doubtful that she had the 'mental capacity' to make it. This was despite the decision being made with the support of her mother, her advocate, a solicitor, and with a doctor at the time expressing the view that she had the mental capacity to make it. Accordingly, the advance decisions were non-binding. E was also found to lack the capacity to litigate, which meant that her solicitor was instructed by a litigation friend to present a case in her 'best interests'. Consequently, E's own solicitor sought a declaration that she should be forcibly fed in her own best interests. The treatment was estimated as giving E a 20% chance of recovering, and E would need to be deprived of her right to liberty for this purpose. The court made the order that forcible feeding was in E's best interests.

¹⁰¹ Re E (Medical treatment: Anorexia) (Rev 1) (2012) EWHC 1639 (COP) available at: http://www.bailii.org/ew/cases/EWHC/COP/2012/1639.html (last accessed: 8 Oct 2013).



Hungary

Population	9,958,453
Persons under guardianship	59,385 ¹⁰²
From which under plenary	33,823
From which under partial	22,870
Date of CRPD ratification	20 July 2007



102 Data provided by the Hungarian National Office for the Judiciary to MDAC on $5\,\mathrm{June}\ 2012$.



'Full limitation of legal capacity': euphemism for plenary guardianship

Currently there are almost 60,000 adults with disabilities in Hungary who are deprived of legal capacity, an enormous proportion compared with other countries. Hungary was the first European country to ratify the CRPD. It was also the first country in the world to adopt new legal capacity legislation inspired by the CRPD: the 2009 Civil Code abolished plenary guardianship and introduced supported decision-making and advance directives. The new law never came into force purely due to party political manoeuvrings. ¹⁰³ In February 2013, another new Civil Code was adopted. It maintains plenary guardianship but calls it "full limitation of legal capacity". Despite the fact that the Code refers to supported decision-making, there is no requirement for a relationship of trust between the supported and the support person, so the so-called support person can be imposed on the person, just like a guardian.

In September 2012 the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) reviewed Hungary, and strongly criticised the government in light of these law reforms which clearly violate Article 12 of the CRPD.¹⁰⁴ The Hungarian government has ignored the CRPD Committee's findings.

Guardianship authority of Visegrád v E.M.

Hungarian legislation does not recognise supported decision-making in a manner that is compliant with the CRPD, however in this case the Court did not place a person with a psycho-social disability under guardianship because of an existing support network around her.

E.M. is a person who was diagnosed with schizoaffective disorder in 2001. Four years later she decided to move to a social care home for elderly people. After she had moved to the home she had several conflicts with the management. In 2009 the director of the institution requested the guardianship authority to initiate proceedings to place E.M. under guardianship. The guardianship authority designated a temporary guardian for her.

During the judicial procedure, two experts recommended that E.M. should be placed under partial guardianship while her own psychiatrist insisted that E.M.'s mental health had improved during the previous year. E.M. and her psychiatrist compiled a list of early symptoms which helped her to identify if her mental health got worse. In the eventuality that her mental health was to deteriorate, her psychiatrist was authorised to change her medication. E.M. is very cooperative with her psychiatrist. The court decided not to place E.M. under guardianship as "a protective net has evolved around E.M. which is

¹⁰³ More information about Hungary's aborted 2009 Civil Code is available at http://www.mdac.info/en/constitutional-court-undermines-legal-status-hunga (last accessed: 2013).

¹⁰⁴ CRPD Committee, Concluding observations: Hungary, adopted on 27 September 2012, (CRPD/C/HUN/CO/1), available at: http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-HUN-CO-1_en.doc (last accessed: 8 Oct 2013).



made of groups of the society. It provides her with sufficient security and guidance for her participation in society and in the solution of the possible difficulties of her illness." The court found that, due to the protective net, "those conditions and events which were perceivable in 2009, before the procedure has started, are not perceivable any more".



Ireland

Population 4,722,028
People under Wardship in 2011 2,277¹⁰⁵

Date of CRPD ratification Not yet ratified



105 Irish Courts Service, Annual Report 2011, Wardship, available at http://www.courts.ie/courts.ie/library3.nsf/66d7c83325e856 8b80256ffe00466ca0/f3f5fb8247bbc825802575f20038272d?OpenDocument (last accessed: 8 Oct 2013).



New legal capacity legislation is a self-imposed prerequisite for ratification

The Republic of Ireland made a commitment to bring its legal capacity laws into conformity with the CRPD before ratifying it. Currently Ireland has a substituted decision-making regime called the Ward of Court system, which was established by the Lunacy Regulation (Ireland) Act 1871. MDAC believes this to be the oldest legal capacity legislation currently in operation in Europe. The system strips the individual of legal capacity and hands decision-making to the court or a person appointed by the court. It is difficult for a person who has been made a ward of court to reverse the decision.

The draft scheme of a new bill on legal capacity was published in 2008.¹⁰⁶ It was essentially a modified guardianship system which NGOs quickly said was not compliant with Article 12 of the CRPD. Much advocacy was carried out around the issue, including holding a number of conferences, one of which MDAC spoke at.¹⁰⁷ In July 2013 the government published the Assisted Decision-Making (Capacity) Bill.¹⁰⁸ While the Bill abolishes the Ward of Court regime and introduces supported decision-making, it still keeps certain forms of substituted decision-making, allowing for the appointment of a "decision-making representative" who may act as substitute decision-maker.

Fionn's story

A mental health expert by experience, Fionn Fitzpatrick spoke of her experience and her hope for the capacity legislation during a conference. Under Ireland's current regime, a person either becomes a ward of court (plenary guardianship), or they are not covered by capacity legislation. However, within a mental health context people can be involuntarily detained and treated against their will, in accordance with their (perceived) 'best interests' as outlined in Ireland's mental health legislation. Fionn spoke of her experience of this and how it took her many years to recover from this system of substituted decision-making.

¹⁰⁶ Scheme of Mental Capacity Bill 2008, available at http://www.justice.ie/en/JELR/Pages/Scheme_of_Mental_Capacity_ Bill_2008 (last accessed: 8 Oct 2013).

[&]quot;Supported decision-making in theory & practice: Ireland's capacity bill" Amnesty International Ireland (29 April 2013) available at www.legalcapacity.eventbrite.ie (last accessed: 8 Oct 2013); "Looking globally, legislating locally: the Irish legal capacity bill" Amnesty International Ireland (3 April 2012), available at http://amnesty.ie/node/2528 (last accessed: 8 Oct 2013); And "Getting it Right: Capacity Legislation and the Convention on the Rights of People with Disabilities" Amnesty International Ireland (30 November 2011) available at http://www.amnesty.ie/content/getting-it-right (last accessed: 8 Oct 2013).

¹⁰⁸ The Assisted decision-Making (Capacity) Bill is available at http://www.oireachtas.ie/viewdoc.asp?DocID=24147&&CatID=59 (last accessed: 8 Oct 2013).

^{109 &}quot;Looking globally, legislating locally: the Irish legal capacity bill" hosted jointly by Amnesty International Ireland and the Centre for Disability Law and Policy, NUI Galway (3 April 2012) Fionn's contribution is available at: http://www.amnesty.ie/node/2481 (at 1:34 into the video) (last accessed: 8 Oct 2013).



During a period of ill-health, as with any illness, Fionn had good days and bad. However, she never felt that she was lacking in the ability to make decisions for herself. Only when she disagreed with a course of action was she told that she didn't have sufficient capacity to make such a decision; such as a course of medication which she knew didn't agree with her. She was treated in a paternalistic fashion, with decisions made for her, without her input.

While she is now in control of her decisions, her experience of powerlessness during this period has not left her. She still harbours fears that she may again be in that position, of being treated against her will. Her biggest fear is of being medicated against her will while being pregnant.

Her medical history puts Fionn at risk of being detained and treated against her will. In order to avoid this she has made an advance directive and lodged it with her former psychiatrist. In this her preferences for psychological supports are clearly spelled out, and in situations where medication may be unavoidable she has stipulated specifically which medication she is willing to take, for how long and in what circumstances.

Despite this she is concerned that her advance directive might be disregarded. Finnn is particularly concerned about the possibility of forced medication during pregnancy, where she may be given medication known to be harmful in utero, medication that she has expressly requested not to be given.

There is no legal recognition for advance directives of people with psycho-social (mental health) conditions in Ireland. There are no support mechanisms in place and there is no CRPD compliance. Without this, people's human rights will continue to be disregarded.



Latvia

Population
Persons under guardianship
From which under plenary
From which under partial
Date of CRPD ratification

2,191,580 2,334¹¹⁰ 2,334 (until 1 January 2013) No data available¹¹¹

1 March 2010



- 110 This data was used by leva Leimane-Veldmeijere, Director of Resource Center for People with Mental Disability, ZELDA in a Conference on legal capacity in Vilnius, on 25 Sept 2012 (data as of August 2011).
- As of 1 January 2013 all persons who were labelled fully legally incapable became persons with restricted legal capacity without restriction on nonmaterial rights. Legal capacity restrictions have to be reviewed at court.



Plenary guardianship abolished

In November 2012, the Latvian parliament adopted new legal capacity legislation abolishing plenary guardianship and introducing partial guardianship, alongside alternatives to guardianship. Latvia's old guardianship law allowed only for the full restriction of a person's legal capacity, a situation commented on by the Constitutional Court in a December 2010 ruling: this significantly influenced the law reform agenda. The judgment found that two provisions of the law which deal with guardianship would become null and void from 1 January 2012. The Court said that the law only provided for total guardianship and "does not allow for partial restrictions of legal capacity or other milder and more appropriate solutions." Latvian lawmakers did not keep the deadline set up by the Constitutional Court and the parliament only adopted significant amendments to the legal capacity legislation almost one year later.

MDAC's Latvian partner organisation, the Resource Center for People with Mental Disability (ZELDA) points out that between 1 January 2012 and 12 February 2012 there was a legal vacuum as no law on legal capacity was in place. On 13 February 2012 temporary regulations entered into force under which in urgent cases a temporary guardian could be appointed but the person retained full legal capacity. Also if the person was able to demonstrate that he/she actually had full legal capacity it could be restored in full.¹¹³

The new law abolishes full deprivation of a person's legal capacity. It introduces a system of partial guardianship, where decisions can be made jointly by an adult with a disability and their guardian. In addition to this, temporary guardianship can be used for up to two years without restricting a person's legal capacity, and the new law introduces advance directives for the first time. The new law also introduces compulsory periodic review of partial guardianship and this is scheduled for every seven years. The new provisions entered into force on 1 January 2013.

Despite these promising developments, supported decision-making as an alternative to guardianship has not yet been put into law. In December 2012, MDAC formally asked the Minister of Justice to introduce supported decision-making and at the beginning of 2013, ministries along with ZELDA developed a proposal to introduce supported decision-making. Meanwhile, ZELDA is in the process of planning a pilot project of supported decision-making.

Judgment of the Constitutional Court of the Republic of Latvia, 27 December 2010, available at: http://zelda.org.lv/en/news/the-constitutional-court-of-latvia-has-adopted-a-decision-in-rc-zelda-clients-j-f-cas-493 (last accessed: 8 Oct 2013).

¹¹³ Using the temporary regulation the Resource Centre for Persons With Mental Disability (ZELDA) represented two clients in court.

In both cases their clients regained full legal capacity.

¹¹⁴ More on the new law: Press release of the Resource Centre for Persons With Mental Disability "ZELDA" from 30 November 2012 "Modernizing the institute of Legal Capacity, the Latvian Parliament adopts extensive legislative amendments" available at: http://zelda.org.lv/en/news/modernizing-the-institute-of-legal-capacity-the-latvian-parliament-adopts-extensive-legislative-amendments-1945 (last accessed: 8 Oct 2013).



Constitutional Court judgment in the case of J.F.

This is the Constitutional Court decision which led to the amendment of legal capacity legislation in Latvia.

"The right to a private life means that an individual has the right to their own private space and the right to live as they choose and enjoy personal development with minimal interference from the state or other persons. These rights encompass the individual's right to be different and to develop qualities and talents that differentiate him or her from others as an individual (...).

Being legally incapacitated significantly affects the person's ability to be independent and make decisions in nearly all areas of life. S/he cannot independently conclude employment, purchase or rental contracts, vote, marry, make a will or perform other actions which would have legal consequences. Therefore, losing their legal capacity significantly restricts a person's right to a private life. The European Court of Human Rights has come to a similar conclusion (...)."

Judgment in case no. 2010-38-01 at para 7. Riga, 27 December 2010



Lithuania

Population 3,525,761 Persons under guardianship 5,900¹¹⁵

From which under plenary

From which under partial

Date of CRPD ratification

No data available

No data available

18 Aug 2010



115 Unofficial data which was commonly used in a conference on legal capacity co-organised by MDAC in September 2012 in Vilnius.



No measures taken, despite ratifying the CRPD

In Lithuania people with disabilities can be declared incapable and placed under guardianship. Only plenary guardianship is available. In 2008, the Ministry of Health established a working group to review legal capacity law and in 2009 the parliament registered some draft laws. In June 2012, MDAC and the Global Initiative on Psychiatry (Vilnius) and the Lithuanian Forum for the Disabled submitted written comments to the UN Human Rights Committee, ¹¹⁶ who subsequently recommended that the authorities take action on forced abortions and sterilisation of women with disabilities who had been deprived of their legal capacity. ¹¹⁷ The Committee also criticised Lithuanian law for not providing legal representation to people with disabilities in cases where they might be placed under guardianship. The Committee also expressed concern that people who had their legal capacity restricted could not apply to a court for review of this procedure.

Following this criticism, MDAC sent a letter to the Lithuanian Prime Minister in August 2012 asking him to uphold the rights of people with disabilities.¹¹⁸ The Ministry of Justice is currently working on a draft which contains provisions on supported decision-making, advance directives, and the possibility of restriction or denial of legal capacity in specific areas of life. In the current proposals, a court would specify the list of fields regarding which the person concerned will partially or fully lose their legal capacity, and the list of deprivation of rights can be so broad that, in fact, this may result in full restriction of a person's legal capacity.

The draft law still allows for the exclusion of the person with disabilities from the court proceedings. In April 2013 MDAC, GIP and the Lithuanian Human Rights Coalition sent a further letter to the Minister of Justice urging the government to adopt a more CRPD-compliant law.

¹¹⁶ See http://mdac.info/sites/mdac.info/files/2012_submission_hrc_lithuania_0.pdf (last accessed: 8 Oct 2013).

¹¹⁷ See http://www2.ohchr.org/english/bodies/hrc/docs/co/CCPR.C.LTU.CO.3_AV.doc (last accessed: 8 Oct 2013).

¹¹⁸ See http://mdac.info/sites/mdac.info/files/lith_let_pm_21aug.pdf (last accessed: 8 Oct 2013).



Supreme Court case of D.S.

MDAC was involved in a case where the Supreme Court of Lithuania annulled a previous court ruling which deprived the applicant of her legal capacity and referred the case to the court of appeal for reconsideration.

"(A) person declared legally incapacitated is deprived many of their rights, including the right to dispose his property and manage related matters, right to work, right to marry, right to vote, right to choose their place of living, right to apply to the court on any issues including a review of his incapacitated status, whereas a legal guardian appointed by a court, and/or a property administrator, become their legal representative for indefinite period of time, and deal with all issues related to a legally incapable person and his property without any special authorisation (Article 3.240 § 1 of the Civil Code)."

Ruling of the Supreme Court of the Republic of Lithuania in civil case No. 3K-3-166/2012, delivered 12 March 2012 (Case Hearing No. 2-02; Categories of the Process Decision: 26.3; 123.4)

D.D. v. Lithuania

In 2000, a court deprived Ms D.D. of her legal capacity in a procedure which was initiated by her adoptive father. Ms D.D. was even denied the opportunity of participating in the procedure to place her under guardianship. Two years later, Ms. D.D. was placed under guardianship and her psychiatrist became her first guardian. After a year, the guardian was relieved of her duties and Ms. D.D.'s adoptive father became her second guardian who placed her in a psychiatric hospital at first, then in a social care institution. Upon the placement in the latter, the director became her third guardian. Ms D.D. was forcibly treated and placed in institutions against her will.

In its judgment following Ms. D.D.'s application to the European Court of Human Rights, the court held that her right to a fair trial had been breached in the guardianship proceedings because she had been denied the opportunity of being heard in person during successive court proceedings.

European Court of Human Rights, Application No. 13496/06, Judgment 12 February 2012



Moldova

Population 3,656,843
Persons under guardianship 5,557¹¹⁹
From which under plenary 3,267
From which under partial 2,290
Date of CRPD ratification 21 Sep 2010



119 See Office of the High Commissioner for Human Rights: The System of Guardianship in Practice in the Republic of Moldova: Human Rights and Vulnerability of Persons Declared Incapacitated. Chisinau, 2013. p. 25, available at http://www.un.md/key_doc_pub/STUDY_The_System_of_Guardianship_in_Practice_in%20_Republic_of_Moldova.pdf (last accessed: 8 Oct 2013).



Plenary guardianship to be abolished

According to Moldovan legislation, a Court can deprive someone of legal capacity if the person "cannot realise or control their actions due to a mental disorder."

In July 2011, MDAC submitted written comments to the Prime Minister on the draft law on social inclusion of persons with disabilities, ¹²⁰ which contained provisions that discriminated against people deprived of legal capacity. The bill was subsequently sent back to the Ministry who was charged with bringing it in line with Moldova's obligations under the CRPD. In December 2011, the law was adopted including a provision that "people with disabilities enjoy equal legal capacity as everybody else in all aspects of life, with measures of protection and legal assistance in the exercise of legal capacity, according to the law in force." In the meantime a working group was set up with the task of preparing a CRPD-compliant legal capacity law. In December 2012, the parliament adopted a revised National Human Rights Action Plan 2011-2014, mandating amendments to the Civil Code and the abolition of plenary guardianship, and the introduction of supported decision-making within the period 2013-14. A new law on supported decision-making has already been drafted.

Excerpt from an interview with a judge from Soroca Court, Moldova

Q: Is the participation of the person to be declared incapacitated at each stage of the trial compulsory and important?

A: "I think that the person's participation is neither necessary nor useful because we speak about people who are mentally inadequate. They just would hinder the proper conduct of the trial. Do you think they might behave in a civilised manner in the courtroom? Their presence in the courtroom is not necessary; the relatives talk for them, while the conclusion is based on the report of the psychiatric expertise."

United Nations Office of the High Commissioner for Human Rights: "The System of Guardianship in Practice in the Republic of Moldova: Human Rights and Vulnerability of Persons Declared Incapacitated." Chisinau, 2013. p. 14.



Northern Ireland

Population 1,806,900

Persons under guardianship No data available
Date of CRPD ratification 8 June 2009





Fusing mental capacity and mental health law

Northern Ireland is currently going through a law reform process that aims to introduce a single law on mental capacity and mental health. The government is currently drafting the core provisions of the Bill. The proposed reforms will introduce a statutory presumption of legal capacity and attempt to regulate situations where there are concerns about an individual's capacity to make decisions or where they have been deemed to lack capacity. It will apply to various areas of life including healthcare, welfare and financial decisions across all settings including hospital and community. If successful, it would be one of the first pieces of legislation of its kind to merge these two areas of law. The proposed law attempts to take a capacity-based approach to mental health and other healthcare areas, welfare and finance interventions in an effort to protect the human rights and dignity of individuals unable to make significant decisions on their own. The goal is to ensure that people who lack mental capacity will be treated on an equal basis.

MDAC has participated in events in Belfast related to the reform and is currently maintaining contacts to provide advice and technical assistance. It is clear, however, that the proposed reforms at they currently stand require further amendment to come into compliance with Article 12 of the CRPD, in order to place a system of supported decision-making much more centrally than at present.

The legal capacity law reform process in Northern Ireland was prompted by the 2002-2007 Bamford Review which looked at law, policy and provisions which affect people with mental health needs or a learning disability in Northern Ireland.

"The vision underpinning the Review is a valuing of those with mental health needs or a learning disability, including their rights to full citizenship, equality of opportunity and self-determination. The vision also looks to a reform of and modernisation of services that will make a real and meaningful difference to the lives of people with mental health needs or a learning disability, to their carers and families. It emphasises promoting the mental health of the whole community and supporting good mental health through preventative action and acknowledges the essential role of carers."

Department of Health, Social Services and Public Safety (2002 -2007) The Bamford Review of Policy, Services and Legislation in Mental Health and Learning Disability in Northern Ireland. DHSSPS, Belfast. Para 1.5.¹²¹

¹²¹ The Bamford Review, available at: http://www.dhsspsni.gov.uk/comprehensive_legislative_framework.pdf (last accessed: 8 Oct 2013).



Poland

Population 38,415,284
People under guardianship in 2008 60,879¹²²
From which under plenary 50,487
From which under partial 10,392
Date of CRPD ratification 25 Sep 2012



122 Adam Bodnar, Anna Śledzińska-Simon, Paweł Osik, Monika Zima: Thematic Legal Study on Mental Health and Fundamental Rights, Poland. EU Fundamental Rights Agency, 2009, para 184, available at: http://fra.europa.eu/sites/default/files/fra_uploads/2158-mental-health-study-2009-PL.pdf (last accessed: 8 Oct 2013).



Interpreting Article 12 so as to deny the right to legal capacity

Polish law allows legal capacity to be fully denied (resulting in guardianship) or partially restricted (resulting in 'curatorship'): there are no alternatives. Deprivation of legal capacity has serious consequences on the rights of people placed under guardianship, since the individual is prohibited from getting married, voting, choosing where to live, or accessing justice.

When Poland ratified the CRPD in 2012 it made an 'interpretative declaration' on Article 12 stating that full deprivation of a person's legal capacity can be regarded as a proper measure when "a person suffering from a mental illness, mental disability or other mental disorder is unable to control his or her conduct." According to the government, deprivation of legal capacity is "a measure indicated in Article 12.4" and can be used "in the circumstances and in the manner set forth in domestic law." It is the view of MDAC that this kind of interpretative declaration amounts to a reservation in violation of Article 46 of the CRPD according to which "(r)eservations incompatible with the object and purpose of the present Convention shall not be permitted."

Kędzior v. Poland

MDAC submitted a third party intervention in the Kędzior case before the European Court of Human Rights. In this case the applicant was partially deprived of his legal capacity and his brother was appointed as his guardian. One year later he was fully deprived of his legal capacity on the ground that his mental health had deteriorated. Following the guardian's request, the applicant was placed in a social care institution. The admission was considered voluntary in law and no judicial approval was required. The applicant asked the court to quash the order depriving him of his legal capacity. However, his motion was rejected on the ground that he had no standing to bring such proceedings.

The European Court of Human Rights found that the social care institution placement constituted an unlawful deprivation of liberty, that there was no effective procedure by which he could challenge his detention, and that he was prevented from directly applying to a court to have his legal capacity restored.

European Court of Human Rights, Application No. 45026/07, Judgment 16 October 2012

MDAC's partner organisation, the Polish Helsinki Foundation for Human Rights continues to litigate the case. The Court awarded Mr Kędzior €10,000 compensation but people under guardianship are not allowed to manage their own finances in Poland. One is left to ask whether compensation awarded by the European Court of Human Rights to the applicant can actually be regarded as "just satisfaction" as he has no access to it at all.



Russia

Population
People under guardianship
From which under plenary
From which under partial
Date of CRPD ratification

142,517,670 300,000 (est.)¹²³ No data available No data available 25 Sep 2012



123 Unofficial data based on the estimation of the Ministry of Health.



Partial guardianship introduced

On 3 May 2012, the Russian President signed a law on ratification of the CRPD,¹²⁴ and on 30 December 2012 the parliament adopted amendments to provisions of the Civil Code related to legal capacity. The law introduced partial guardianship and will only come into force on 2 March 2015.¹²⁵

The amendments are based on the judgment of the Russian Constitutional Court in the the case of *Delova*, ¹²⁶ a case in which the Court held that "(t)he federal legislator must – based on the requirements of the Constitution of the Russian Federation and in view of this judgment – amend before 1 January 2013 the existing civil regulation with the view of achieving the most comprehensive protection of the rights and interests of the persons with mental disorders." According to the new provisions, a person with restricted legal capacity will be able to carry out everyday transactions and more serious ones with the consent of their guardian, who will receive and spend any salary, pension or other income of the person under trusteeship in his/her interest, and with the consent of the guardianship authority. The court can restrict the right of the person to spend their social security or pension. The guardian shall assist the person with restricted legal capacity in exercising their rights and duties, and shall protect them from the abuse of third parties. The amendments to the Civil Code also introduced the requirement for a guardian to take into account the person's opinion. Where this is not possible, the guardian is required to take into account information of his preferences obtained from his parents or other carers.

As a result of the 2008 Shtukaturov judgment 127 at the European Court of Human Rights, the 2009 Constitutional Court decision in the same case, 128 and the concluding observations of the 2009 UN Human Rights Committee, 129 MDAC carried out intensive advocacy in coalition with Russian NGOs. This led to the Russian parliament adopting procedural safeguards in April 2011 to protect people with disabilities placed under guardianship and detained in psychiatric hospitals. 130 The safeguards include the obligations on courts to notify an individual of a legal capacity case initiated against him or her and always conduct legal capacity proceedings with the participation of the person concerned. Under the new rules, a person deprived of legal capacity has the right to consent to or refuse any healthcare intervention, and may apply to court in order to seek restoration of his or her legal capacity.

¹²⁴ See http://www.mdac.info/en/10/05/2012/russia_ratifies_crpd (last accessed: 8 Oct 2013).

¹²⁵ Federal law of 30 December 2012 no. 302-FZ "On amendment of chapters 1, 2, 3 and 4 of part 1 of the Civil Code of the Russian Federation".

¹²⁶ Case no. 15-P, 27 June 2012. See http://mdac.info/en/28/06/2012/Russian_Constitutional_Court_criticises_abusive_guardianship_law (last accessed: 8 Oct 2013).

¹²⁷ See http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-85611 (last accessed: 8 Oct 2013).

¹²⁸ See http://www.mdac.info/en/content/russia-constitutional-court-forges-way-out-discrimination-people-mental-disabilities (last accessed: 8 Oct 2013).

¹²⁹ See http://www2.ohchr.org/english/bodies/hrc/docs/co/CCPR.C.RUS.Co.6.PDF (last accessed: 8 Oct 2013).

¹³⁰ See http://mdac.info/en/news/russia-strategic-litigation-leads-law-reform (last accessed: 8 Oct 2013).



It is clear that the reforms adopted, whilst limiting the worst effects of the system of plenary guardianship, fall short of the requirements of Article 12 of the CRPD. This, combined with the continuing delays in enacting comprehensive legislative reform, brings to light the need for further reform.

Lashin v. Russia

Dmitri Bartenev, MDAC senior legal monitor represented the applicant in this case, in which the European Court of Human Rights addressed the automatic loss of the right to marry of a person deprived of their legal capacity. The Court took the view that a blanket ban on the right to marry is a violation of the European Convention on Human Rights.

"The Court observes that the applicant's inability to marry was one of many legal consequences of his incapacity status. The Court has already found that the maintenance of that status (the only measure of protection applicable under the Russian Civil Code to mentally ill persons) was in the circumstances disproportionate and violated Article 8 of the Convention (...). In other words, the applicant was unable to marry primarily because of (...) two major factors (...), namely the deficiencies in the domestic decision-making process and the rigidity of the Russian law on incapacity" (paragraph 124).

European Court of Human Rights, Application No. 33117/02, Judgment 22 January 2013

Shtukaturov v. Russia

As explained earlier in this report, Mr Shtukaturov was placed under guardianship of his mother in proceedings about which he was not aware and was not asked to participate. His mother subsequently placed him in a psychiatric hospital without his consent. He spent seven months there and was denied the opportunity of meeting his lawyer.

The European Court of Human Rights said that deprivation of legal capacity constitutes a "very serious" interference with a person's private life and found that the fact that it was applied for an indefinite period, and could not be challenged by the person under guardianship, constituted a violation of the European Convention on Human Rights.



"The Court notes that the interference with the applicant's private life was very serious. As a result of his incapacitation the applicant became fully dependent on his official guardian in almost all areas of life. Furthermore, 'full incapacitation' was applied for an indefinite period and could not, as the applicant's case shows, be challenged otherwise than through the guardian, who opposed any attempts to discontinue the measure" (paragraph 90).

Mr. Shtukaturov also brought his case before the Russian Constitutional Court. He argued that the Russian guardianship system, which allows only for full 'incapacitation', is not a proportionate measure and is discriminatory, that there was no judicial review of civil psychiatric confinement in the case of persons declared 'incapable', in violation of the constitutional right to liberty; and there was no standing of persons declared 'incapable' in civil proceedings, in violation of the constitutional right of judicial protection of one's rights. As a result of the complaint, the Constitutional Court quashed several legal provisions, including the involuntary placement of persons deprived of their legal capacity in a psychiatric hospital solely with the consent of the guardian, and without the review of a court.

European Court of Human Rights, Application No. 44009/05, Judgment (merits) 27 March 2009, Judgment (just satisfaction) 4 March 2010
Constitutional Court, Judgment No. 4-P, decision 27 February 2009



Slovakia

Population 5,483,088

Number of legal capacity related cases arrived to courts in 2011 1,848¹³¹

From which requesting full deprivation of legal capacity 1,761

From which requesting limitation of legal capacity 60

Date of CRPD ratification 26 May 2010



Data used in the Slovakian Initial Report to the CRPD Committee, available at http://www.ohchr.org/Documents/HRBodies/CRPD/Future/CRPD-C-SVK-1_en.doc at page 87. (last accessed: 8 Oct 2013).



Legal capacity law reform on the Government's agenda

In Slovakia a court can deprive or restrict legal capacity where the person concerned is "totally unable to perform legal acts as a result of non-temporary mental disorder" or he/she is "able to perform only certain legal acts as a result of a non-temporary mental disorder." In the latter case, the court sets out the areas where the person's legal capacity is limited. Once a person is deprived of their legal capacity they are automatically denied the opportunity of exercising a wide range of rights including the right to marry, vote and bring up children.

Currently, legal capacity law reform is on the agenda of the Slovak Government. In May 2012 it pointed out in its State report to the CRPD Committee that legal capacity legislation is under review.¹³²

Constitutional complaint of E.T.

In November 2012, the Constitutional Court issued a judgment in a case regarding the deprivation of legal capacity of the applicant, E.T., and found violations of the right to legal capacity, right to integrity and privacy, right to protection against unlawful interference in private and family life, and the right to judicial protection under the Constitution of the Slovak Republic. The Constitutional Court also found violations of the right to a fair trial, right to a private and family life and the right to freedom from discrimination under the European Convention on Human Rights, as well as the right to legal capacity under the UN Convention on the Rights of Persons with Disabilities.

"Within the constitutional significance of rights of a person, the Constitutional Court in particular puts forward that their deprivation/restriction ex contitutione primarily considers the interest of the very (concerned) person, and only then the interest of the public or of third persons. Unfortunately, past and even current practice of the general courts shows prioritising of the public interest and interest of third persons at the expense of the interest of the concerned person."

Case No. I. ÚS 313/2012-52, Judgment 28 November 2012



Spain

Population
People under guardianship
Date of CRPD ratification

47,370,542 No data available 30 Mar 2007





Legislative delays result in on-going restriction of legal capacity

Spain ratified the CRPD in 2007 and the Spanish government made concrete steps to reform its legal capacity law by adopting Act 1/2009. The final provision of this piece of law gave the government six months to present a draft to bring Spanish legal capacity provisions in line with the CRPD. The government missed the deadline. A 2010 governmental report 133 suggested changes which were not based on CRPD standards. 134

Act 26/2011 of August 2011 established a new deadline and allowed a period of one more year. The government failed to keep this deadline too. A new Act¹³⁵ was adopted which established a third deadline. In the meantime the CRPD Committee reviewed Spain in September 2011 and recommended that it, "review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences."¹³⁶

The current deadline for the Spanish government to comply with the CRPD is 31 December 2013.¹³⁷ As a consequence of the delay in launching law reform, the legal system still allows for deprivation and limitation of legal capacity¹³⁸ and for extending paternal authority, which means that paternal authority¹³⁹ does not end when a so-called "incapable minor" reaches the age of 18.

¹³³ Draft report from July 2010, available at: http://www.poderjudicial.es/cgpj/es/Temas/Justicia_y_Discapacidad/Actividades/relacionados/Documento_de_trabajo_sobre_la_posible_reforma_del_Codigo_civil__del_Estatuto_Organico_del_Ministerio_Fiscal_y_de_la_Ley_1_2000_de_Enjuiciamiento_Civil_en_materia_de_modificacion_judicial_de_la_capacidad_y_de_las_medidas_de_proteccion_y_apoyo_de_menores_y_de_personas_con_capacidad_modificada_judicialmente#bottom (last accessed: 8 Oct 2013).

¹³⁴ See for example, Red CDPD Report "The time for rights", number 23, Legal Capacity and Disability, proposals for the normative adaptation of the Spanish legislation to Art. 12 of the CRPD, P. 39, 40, available at: http://www.uc3m.es/portal/page/portal/instituto_derechos_humanos/sala_prensa/comunicados_de_prensa/informe_23/informe_23.pdf (last accessed: 8 Oct 2013).

¹³⁵ Act 12/2012 of 26 December 2012.

¹³⁶ CRPD Committee, Concluding Observations: Spain, para 34 (CRPD/C/ESP/CO/1).

¹³⁷ Fifth Final provision, Law 12/2012, available at: http://www.boe.es/boe/dias/2012/12/27/pdfs/BOE-A-2012-15595.pdf (last accessed: 8 Oct 2013).

¹³⁸ Articles 199 and following, Spanish Civil Code.

^{139 &}quot;La patria potestad prorrogada." Article 171, Spanish Civil Code.



Ukraine

Population
Persons under guardianship
From which under plenary
From which under partial
Date of CRPD ratification

44,854,065 48,000(est.)¹⁴⁰ No data available No data available 4 Feb 2010



140 See http://helsinki.org.ua/en/index.php?id=1337406783 para 5.23 (last accessed on 8. Oct 2013).



Pilot project on supported decision-making being implemented

The Civil Code sets out a procedure whereby a court can strip the person of legal capacity if a chronic and stable mental disorder prevents him/her from controlling his/her actions and understanding their meaning. Guardians are requested to act in the person's "best interest" but there is no mechanism to check whether this happens. Legal capacity can only be restored following a request by the guardian or the guardianship authority: the person under guardianship may not initiate proceedings. Currently, MDAC's Ukrainian partner organisation, the All-Ukrainian NGO Coalition for Persons with Intellectual Disability is developing a pilot project on supported decision-making through formation of individual support schemes.

Nataliya Mikhaylenko v. Ukraine¹⁴¹

Ms Mikhaylenko is a woman with psycho-social disabilities and was placed under guardianship in 2007. Her mental health improved and in 2009 the guardian applied for restoration of her legal capacity, but the court did not allow this, due to the guardian's repeated failure to appear in court. In 2010 the applicant herself applied to the court to have her legal capacity restored. Her application was dismissed by the court because of the law which does not allow a person under guardianship to apply to have the guardianship lifted.

MDAC represented Ms Mikhaylenko in this case, the first European Court of Human Rights case about guardianship in Ukraine.

European Court of Human Rights , Application No. 49069/11, Judgment 30 May 2013

¹⁴¹ More on the background of the case: http://www.mdac.info/en/30/05/2013/ukraine-system-guardianship-becomes-latest-target-critique-european-court-human-rights (last accessed on 8. Oct 2013).



Chapter 8: Further reading

The following sources provide more information about Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and the right to legal capacity, as well as more detailed discussions about supported decision-making.

We recommend that readers take a look at our website for up-to-date developments on the right to legal capacity – **www.mdac.info**.

Advocacy for Inclusion, Supported Decision Making, Legal Capacity and Guardianship: Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory, (Canberra City, 2012)

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Dhanda, A., "Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?" Syracuse Journal of International Law and Commerce: 34, 429, (2007), 457-458

Dinerstein, R. D., "Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making", 19 Human Rights Brief (2012)

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European Union Agency for Fundamental Rights (FRA), Involuntary placement and involuntary treatment of persons with mental health problems, (Vienna, 2012)



European Union Agency for Fundamental Rights (FRA), Legal capacity of persons with intellectual disabilities and persons with mental health problem (Vienna 2013)

Fennell, P. & Khaliq, U. "Conflicting or complementary obligations? The UN Disability Rights Convention on Human Rights and English law", European Human Rights Law Review, 6 (2011) 662-674

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Mental Disability Advocacy Center, Guardianship and Human Rights in Serbia: Analysis of Guardianship Law and Policy (Budapest, 2006)

Mental Disability Advocacy Center, Guardianship and Human Rights in Bulgaria: Analysis of Law, Policy and Practice, (Budapest, 2007)

Mental Disability Advocacy Center, Guardianship and Human Rights in Russia: Analysis of Law, Policy and Practice, (Budapest, 2007)

Mental Disability Advocacy Center, Guardianship and Human Rights in Hungary: Analysis of Law, Policy and Practice, (Budapest, 2007)

Mental Disability Advocacy Center, Guardianship and Human Rights in the Czech Republic: Analysis of Law, Policy and Practice, (Budapest, 2007)



Minkowitz, T., "The United Nations Convention on the Rights of Persons with Disabilities and the right to be free from non consensual psychiatric interventions", 34 Syracuse Journal of International Law and Commerce (2006-7)

Ortoleva, S., "Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System Disability-Inclusive Development", 17 ILSA Journal of International and Comparative Law (2010-11)

Parker, C., "Forgotten Europeans, Forgotten Rights: The Human Rights of Persons Placed in Institutions," United Nations Office of the High Commissioner for Human Rights, Brussels, 2011

Šimokovic, L., et al, "Practicing Universality of Rights: Analysis of the implementation of the UN Convention on the Rights of Persons with Disabilities in view of Persons with intellectual Disabilities in Bosnia and Herzegovina, Kosovo, Serbia", People in Need, 2012

Werner, S., "Individuals with Intellectual Disabilities: A Review of the Literature on Decision-Making since the Convention on the Rights of People with Disabilities (CRPD)", 34 Public Health Reviews (2012)