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WHO GETS TO DECIDE?

**Right to legal capacity for persons
with intellectual and psychosocial disabilities**

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SUMMARY

The right of persons with disabilities to make choices about their lives and enjoy legal capacity on an equal basis with others is one of the most significant human rights issues in Europe today. Being recognised as someone who can make decisions is instrumental in taking control over one's life and participating in society with others.

Having legal capacity enables us to choose where and with whom we want to live, to vote for the political party we prefer, to have our health care decisions respected, to control our own financial affairs and to have access to cinemas and other leisure activities. Without it we are non-persons in the eyes of the law and our decisions have no legal force. This is still the reality for hundreds of thousands, if not a million, Europeans with intellectual and/or psychosocial disabilities put under guardianship regimes.

The UN Convention on the Rights of Persons with Disabilities offers a response to these concerns through its Article 12 on the equal recognition before the law. In fact, this Article provides a paradigm shift in policies towards persons with disabilities; it signals a deeper understanding of equality.

The bulk of European legal capacity systems are out-dated and in urgent need of law reform. The assumption of legal capacity, which all adults of majority age should enjoy, has to be extended to persons with disabilities. It redirects our focus away from personal deficiencies towards putting into place supports that enable individuals to make decisions for themselves and expand their capacities to do so.

This Issue Paper describes the challenges faced by Council of Europe member states in dealing with the issue. These include the flaws of current guardianship systems and procedures, the automatic loss of human rights of those placed under guardianship regimes and the pressing need to develop support alternatives giving persons with disabilities equal opportunities to shape their life paths. The paper outlines the applicable international human rights framework, including the relevant case-law from the European Court of Human Rights. It concludes with examples of good practice to show the way forward.

The Commissioner's Recommendations to member states for bringing their legal systems on legal capacity in line with their human rights obligations are published at the beginning of the document.

THE COMMISSIONER'S RECOMMENDATIONS

In order to ensure the effective enjoyment of the right to legal capacity by persons with intellectual and/or psychosocial disabilities, the Commissioner for Human Rights calls on Council of Europe member states to:

1. Ratify the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol.
2. Review existing legislation on legal capacity in the light of current human rights standards and with particular reference to Article 12 of the UN Convention on the Rights of Persons with Disabilities. The review should identify and remedy possible flaws and gaps depriving persons with disabilities of their human rights in relation to legislation concerning, inter alia, guardianship, voting rights and compulsory psychiatric care and treatment.
3. Abolish mechanisms providing for full incapacitation and plenary guardianship.
4. Ensure that persons with disabilities enjoy the rights to property, including the right to inherit property and to control their own financial affairs, to family life, to consent to or reject medical interventions, to vote, to associate freely and to access justice on an equal basis with others. No one should be automatically deprived of these rights because of an impairment or disability or due to being subjected to guardianship.
5. Review judicial procedures to guarantee that a person who is placed under guardianship has the possibility to take legal proceedings to challenge the guardianship or the way it is administrated as long as guardianship regimes still remain valid.
6. End 'voluntary' placements of persons in closed wards and social care homes against the person's will but with the consent of guardians or legal representatives. Placement in closed settings without the consent of the individual concerned should always be considered a deprivation of liberty and subjected to the safeguards established under Article 5 of the European Convention on Human Rights.
7. Develop supported decision-making alternatives for those who want assistance in making decisions or communicating them to others. Such alternatives should be easily accessible for those in need and provided on a voluntary basis.
8. Establish robust safeguards to ensure that any support provided respects the person receiving it and his or her preferences, is free of conflict of interests and is subject to regular judicial review. The individual concerned should have the right to participate in any review proceedings along with the right to adequate legal representation.
9. Create a legal obligation for governmental and local authorities, the judiciary, health care, financial, insurance and other service providers to provide reasonable accommodation to persons with disabilities who wish to access their services. Reasonable accommodation includes the provision of information in plain language and the acceptance of a support person communicating the will of the individual concerned.
10. Involve persons with intellectual and psychosocial disabilities and the organisations representing them actively in the process of reforming legislation on legal capacity and developing supported decision-making alternatives.

*“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.
WOULD YOU WANT THIS TO HAPPEN TO YOU?
Wouldn't you have the feeling that you have lost your dignity and want it back? “1*

1. Introduction

Access to human rights for people with intellectual and psychosocial disabilities² still remains wishful thinking in most parts of Europe. Positive action is urgent and necessary to speed up the process of inclusion. In 2009, the Parliamentary Assembly of the Council of Europe passed a Resolution listing key areas to be prioritised. The first area mentioned by the Parliamentary Assembly is the topic of this paper, i.e. the reform of current and outdated legal capacity systems.³

The right of persons with disabilities to enjoy legal capacity on an equal basis with others, coupled with the right to support in order to exercise one's legal capacity, has gained the attention of the human rights community in recent years. Being recognised as someone who can make decisions is instrumental in taking control over one's life and engaging in society with others. Having legal capacity enables us to make decisions ranging from the profound (choosing where and with whom to live) to the everyday (to buy a bus ticket, to sign a lease, to consent to medical treatment). Without it we are non-persons in the eyes of the law and our decisions have no legal force. Third parties make decisions for us. This merger of our personhood into that of someone else's has been described as 'civil death'. It affected women in the past and is still the reality for a large number of Europeans with intellectual and psychosocial disabilities put under guardianship regimes.

Some progress has been made. Milestone judgments have been given by the European Court of Human Rights (the Court), and more cases are pending before it. Legal reforms are under way in several Council of Europe member states. Constitutional Courts in the Russian Federation and the Czech Republic have deemed the deprivation of legal capacity and placement under plenary guardianship of persons with disabilities unconstitutional under certain circumstances.⁴ Reforms are being discussed in both these countries as well as in France, Hungary, Ireland, Latvia, Portugal, Slovakia and Slovenia. Norway and Sweden are reviewing their legislation on compulsory psychiatric treatment and care.

These reform trends have come about because of a growing awareness of the unsatisfactory nature of traditional guardianship law. The future is anticipated in Article 12 on the equal recognition before the law of the UN Convention on the Rights of Persons with Disabilities (CRPD) – a provision that marks not just an evolution but also a revolution in thinking about legal capacity and its underlying basis, legal personhood (see section 4.1). It is evolutionary in that it

¹ Citation from the 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*, Jan. 31, 2006.

² This paper applies the description of persons with disabilities laid down in the Convention on the Rights of Persons with Disabilities, article 1: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." Persons with intellectual disabilities hence include those who experience difficulties in their intellectual functioning, for example persons with Down's syndrome. Persons with psychosocial disabilities include those who are diagnosed with and/or experiencing mental health problems, e.g. bipolar disorder, autism or schizophrenia.

³ Parliamentary Assembly, Resolution 1642 (2009) "Access to rights for people with disabilities and their full and active participation in society", adopted on 26 January 2009.

⁴ For more information see http://www.mdac.info/czech-republic-constitutional-court-finds-deprivat_and <http://mdac.info/content/russia-constitutional-court-forges-way-out-discrimination-people-mental-disabilities>.

builds on best practices developed in some countries in close cooperation with the disability movement (see further chapter 5) and encourages reform. The revolution – or the paradigm shift – of Article 12 is probably not quite precise about the ultimate shape European legal capacity law should take but it is clear enough to enable us to characterise the bulk of European legal capacity systems as out-dated. It compels law reform to assume that everybody enjoys legal capacity and redirects our focus away from deficiencies (which are in fact universal and not confined to persons with disabilities) towards supports that enable individuals to make decisions for themselves and expand their capacities to do so. The notion of ‘supported decision-making’ simply builds on this universal reality and extends it to persons with disabilities.

This Issue Paper does not provide a one-size-fits-all formula to solve the question but discusses the challenges member states face in this area: the future (if any) of guardianship systems, the automatic loss of human rights of those placed under guardianship regimes including the lack of access to justice as well as the need to develop alternatives for persons who want support to exercise their legal capacity. It outlines the international human rights framework granting persons with intellectual and psychosocial disabilities legal capacity on an equal basis with others. It concludes with examples of good practice to demonstrate the way forward.

1.1 What is legal capacity?

Legal capacity can be described as a person's power or possibility to act within the framework of the legal system. In other words, it makes a human being a subject of law. It is a legal concept, a construct, assigned to most people of majority age enabling them to have rights and obligations, to make binding decisions and have them respected. As such, it facilitates personal freedom. It enables us to take up a job, get married and inherit property among other things. It also protects the individual against (some) unwanted interventions. Adults with legal capacity can for example effectively refuse any medical treatment that they do not want to receive.

Legal capacity is also something most of us take for granted. Most Europeans above 18 years' old are never questioned about their capacity to make decisions and choose their life paths. This does not mean that the majority does not seek advice from, or even hand over, certain decisions to family and friends whom they trust. But wishing and enjoying such assistance does not trigger any legal consequences for most of us. We retain our legal capacity to seek and disregard the advice of others, to take risks, to make mistakes and learn (or not learn) from them.

Some jurisdictions make a distinction between capacity to have rights and capacity to act or exercise these rights. The first part includes the right to be a subject before the law; to be someone who can own property and possess human rights and other rights provided for by domestic legislation. The second part (to exercise rights) goes further and includes the power to dispose of one's property (i.e. to use it, sell it, give it away or destroy it) and claim one's rights before a court.⁵ Human rights scholars argue convincingly that article 12 of the CRPD vests persons with disabilities with *both* of these aspects of legal capacity.⁶ In other words, the capacity to hold rights automatically entails the capacity to exercise them with appropriate supports acceptable to and chosen by each individual.

1.2 Why is legal capacity important?

Reforming current mechanisms for legal capacity is one of the most significant human rights issues in Europe today. First of all, legal capacity goes beyond decision-making; it is about what it

⁵ During the negotiations for the convention, some States Parties wished to limit the CRPD to only deal with capacity for rights, whereas others, including representatives from the disability movement, argued strongly for the convention to cover both aspects.

⁶ See e.g. Amita Dhandu, 'Legal capacity in the Disability Rights Convention: Strangehold of the past or lodestar for the future?' 34 Syracuse Journal of International Law & Commerce, 2007, p. 429ff; Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity', prepared for the Law Commission of Ontario, October 2010, p 16; and Tina Minkowitz, 'The United Nations Convention on the Rights of Persons with Disabilities and the right to be free from nonconsensual psychiatric interventions' 34 Syracuse Journal of International Law & Commerce, 2007, page 405ff.

means to be human.⁷ The life choices we make are part of who we are. Several human rights have been established to protect individuals against undue interference with these choices, e.g. freedom of religion, thought and conscience, the right to marry and to found a family and the right to respect for private and family life. Without legal capacity, many, if not all, of these rights become meaningless. What is the point of having the right to marry and found a family if someone else, your guardian, is the only one who can make legally effective decisions in that area?

Secondly, deprivation of legal capacity is a problem affecting a large group of people. Hundreds of thousands, if not a million, of Europeans with intellectual and/or psychosocial disabilities are put under, sometimes life-long, guardianship.⁸ Also systems aiming to be shorter-term tend to become more or less permanent. This applies both to persons with intellectual disabilities as well as those diagnosed with mental illnesses considered to be more or less permanent (schizophrenia, for example). The appointment of a guardian is usually based on a medical report. Once such a report has been written it is difficult to revoke the guardian because, from a medical point of view, the individual often does not get better.⁹ However, if given the right support and the opportunity to practice, the capacity of these individuals to make choices and communicate them to others could develop considerably.

Thirdly, a label of incompetence can easily become a self-fulfilling prophecy. If not given any opportunities to make decisions, how can we learn to do so and take responsibility for our choices? The loss of control over one's life that follows from the deprivation of legal capacity has negative effects on the person's sense of the self.¹⁰ When third parties systematically make all their decisions *for* them, persons with disabilities learn helplessness and dependence. Individuals who are no longer addressed as primary masters of their own life are also more likely to be diminished in the eyes of third parties, such as service providers, community members, public officials and others interacting with the individual. This diminishment contributes to the risk of stereotyping, objectification, and other forms of exclusion which people with disabilities disproportionately face, which in turn adds to the experience of powerlessness and the vulnerability to abuse and neglect.¹¹

2. European challenges

All European jurisdictions have mechanisms dealing with persons with psychosocial and/or intellectual disabilities who are not considered able to make 'informed' decisions, i.e. understand implications of certain decisions or appreciate the reasonable foreseeable consequences of different options. Different models have been and are still used to attribute incapacity to persons with disabilities. The "status approach" equates certain impairments/disabilities with incapacity to make decisions in some or all areas of life. With this model the very existence of a particular impairment is sufficient to strip the individual of legal capacity, regardless of the individual's actual capacities.

The "outcome approach" instead focuses on the 'reasonableness' of the decision reached by the individual. The typical example is the person with a psychosocial disability seeking treatment at a psychiatric hospital. The decision to seek and accept treatment is almost always accepted as a valid decision. If the individual however wants to discontinue his/her treatment, that decision is likely to be questioned on the basis that the individual is not competent to understand his/her best interest.

⁷ Gerard Quinn, 'Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD', HPOD Conference, Harvard Law School, 20 February 2010.

⁸ Peter Bartlett *et al*, *Mental Disability and the European Convention*, p. 155. Figures are based on research conducted by the Mental Disability Advocacy Centre (MDAC) on guardianship systems in Bulgaria, Croatia, Czech Republic, Georgia, Hungary, Russia and Serbia.

⁹ See, e.g. Swedish Disability movement's alternative report to the UN Committee on the Rights of Persons with Disabilities, 2011, para 204.

¹⁰ Dhanda, p. 436.

¹¹ Bach and Kerzner, p. 7.

Lastly, the “functional approach” concentrates on the individual’s cognitive capacities, i.e. his/her ability to understand the nature and consequences of a certain decision. An impairment or disability is applied as a threshold condition in that only persons with such conditions run the risk of having their capacity questioned. To retain one’s legal capacity, the individual has to be able to demonstrate the capacity to make informed decisions on his/her own.¹²

All of these approaches are objectionable. The status approach rests on stereotypes and ignores the person’s actual abilities. The outcome approach is contradictory and does not afford persons with disabilities the dignity of making mistakes and taking risks like the rest of us. The functional approach has, so far, given too little attention to the importance of support. The functional approach may yet have a future, not as a yardstick by which to withdraw capacity as in the past, but rather as a measure to help determine what type of supports should be made available to the individual.

The consequence of assigning incapacity is often to hand over the decision-making power to a third party. The situations and individuals such arrangements apply to and the level of involvement of the individual concerned vary a great deal across Europe. The aim here is not to give a full description of each Council of Europe member state, but to point out the major problems with current systems from a human rights point of view.¹³

2.1 Incapacitation procedures and guardianship systems

A large number of Europeans with intellectual and/or psychosocial disabilities are deprived of their legal capacity and put under some form of guardianship. Exact figures are unknown since there is no standardised way of collecting data, but estimates reach about one million adults in the region.¹⁴ Two main guardianship models are common practice: plenary and partial guardianship. Persons under partial guardianship keep the main bulk of their civil rights but certain capacities are transferred to a legal representative, most commonly the power to manage financial affairs. Those under full or plenary guardianship, on the other hand, lose all or almost all of their civil rights. The involvement of the guardian is then necessary to make legally effective decisions in most areas of life. Although partial guardianship is the preferred option between the two, also such systems tend to ‘spill over’ into other areas. Reports indicate that partial guardians have too much control over the lives of their wards who are not always aware of which decisions are for them to make and which belong to the guardian, or of their right to be involved also in those decisions where the guardian has the final say.¹⁵

While providing protection against some types of abuse, experience shows that guardianship systems can end up facilitating abuse from guardians and third parties. Examples include guardians putting their client in a hospital or a social care home against the individuals’ will, economic maladministration and other types of abuse and neglect. Processes leading to the deprivation of legal capacity and the appointment of legal representatives are also seriously flawed. Incapacitation procedures take place behind the individuals’ back. Even where the national law provides the right to be notified and to be present and heard in court, such a requirement is often complemented by a frequently applied possibility to go ahead without the individual if his/her participation in court is deemed detrimental to his/her health.¹⁶

Lack of free and effective legal representation during judicial proceedings is another problem, severely curtailing the individuals’ possibilities to challenge an application for guardianship.¹⁷

¹² Dhanda, pp. 431-432.

¹³ For more in-depth information see MDAC’s reports of guardianship in Bulgaria, Croatia, Czech Republic, Georgia, Hungary, Russia and Serbia, and Inclusion Europe’s study “The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs, Report of a European Study”.

¹⁴ Written submission by the Mental Disability Advocacy Center (MDAC) as *amicus curiae* pursuant to article 36(2) of the European Convention on Human Rights in accordance with Rule 44(2) of the Rules of Court in the case *Stanislaw Kedzior v. Poland* (Application no. 45026/07), 3 September 2009, para 4.

¹⁵ Inclusion Europe’s study, volume 2, p. 83.

¹⁶ MDAC’s reports on guardianship: Czech Republic, p 36; Georgia, p 26; Russia, p 27; and Serbia, p 33.

¹⁷ Mary Keys ‘Legal capacity reform in Europe: An urgent challenge’ in European Yearbook of Disability Law, G. Quinn and L Waddington (eds.), volume 1, page 80; cf. *Airey v. Ireland*, Application no. 6289/73, 9 October 1979, para 24.

Lastly, control mechanisms and review procedures fail to monitor the guardian's actions and omissions properly. Guardians are often expected to provide annual activity reports to the municipality or other supervisory authority. The primary focus of these reports tends to be financial matters and the reports seldom provide information on other decisions taken by the guardian. The reports may also remain with the authority without being communicated to the individual concerned. In some countries the individual even lacks the power to request to see the report. Family members acting as guardians are in some countries exempted from the reporting obligation altogether, leaving no oversight of their activities.¹⁸

2.2 Automatic loss of human rights

Loss of the power to manage one's property and financial affairs is the typical consequence of incapacitation and guardianship. One of the core functions of guardians is to take over the responsibility for the adult's financial means. The extent to which the individual loses capacity to dispose his/her material means differs between countries. Partial guardianship systems may allow the individual to manage everyday decisions on his/her own but place more important decisions including those involving large sums of money with the guardian.¹⁹ Jurisdictions providing for plenary guardianship tend to deprive the individual of almost all authority to make legally valid transactions.

Other rights are affected as well, including the right to work, to marry and to political participation. A recent report from the European Union Agency for Fundamental Rights (FRA) shows that the majority of EU member states links the right to political participation to the legal capacity of the individual. As a result, these countries have an automatic or quasi-automatic provision in their legal systems excluding persons with psychosocial and/or intellectual disabilities whose legal capacity has been restricted from the right to vote. And this is regardless of whether these individuals actually understand the idea of voting or not.²⁰

Legal capacity is essential for benefitting from the principle that medical interventions must be based on free and informed consent.²¹ In some European countries guardians are automatically empowered to take decisions on behalf of the individual also in the sphere of health care. Consent from the guardian may lead to hospitalisation and/or medical interventions being considered as voluntary, despite the absence of consent from the individual concerned. The interventions might even be against the individual's expressed will and still be considered voluntary in a legal sense. In other countries guardians or other legal representatives cannot make health care decisions. However, non-consensual interventions in the psychiatric field are still possible in most countries if a doctor deems them necessary and a court confirms.

Lastly, persons divested of their legal capacity lose their right to appear before court and therefore lack effective remedies to challenge their incapacitation, their legal representatives undertakings and any other legal matter they would otherwise be able to bring before a court.

2.3 Lack of support alternatives

Persons with intellectual and/or psychosocial disabilities should have the possibility to receive support, also in the form of a discussion partner, for communicating with the authorities, applying for a housing benefit or making decisions about health care or choice of accommodation. The sad

¹⁸ MDAC reports on Bulgaria, pp. 59-60; Czech Republic, pp. 65-66; Hungary, p. 57. See also Inclusion Europe's study, volume 3, pp. 353 and 390.

¹⁹ MDAC reports on Bulgaria, p. 48; Czech Republic, pp. 53-54; Georgia, pp. 40-41; Hungary, p. 44; Russia, pp. 42-43 and Serbia, pp. 53-54

²⁰ European Union Agency for Fundamental Rights, The right to political participation of persons with mental health problems and persons with intellectual disabilities, October 2010, p. 10.

²¹ See e.g. *Pretty v. The United Kingdom*, Application no. 2346/02, 29 April 2002, para 63, which states that: "In the sphere of medical treatment, the refusal to accept a particular treatment might, inevitably, lead to a fatal outcome, yet the imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention". See also *Herczegfalvy v Austria*, Application no. 10533/83, 24 September 1992, paras 82-83 and 86, where the Court concluded that medical treatment without consent is not contrary to Article 8 if the State can convincingly show that it was necessary and the individual lacked capacity to give informed consent.

truth is that most Europeans with intellectual and/or psychosocial disabilities who would like to have such support are instead asked to give up their legal capacity, i.e. their capacity to be in charge of their lives, and accept that someone else takes decisions on their behalf. Conscientious legal representatives will ask them for their opinion and do their utmost to act according to the will of their client, but the individual will still have lost the right to have a final say in decisions concerning his/her person.

3. Equal rights for persons with disabilities: a paradigm shift

The so called 'paradigm shift' in disability policy is often described as a shift in viewing persons with disabilities from objects to subjects. This signifies a move from charity to a rights-based approach and from paternalism to empowerment. We should also consider it as a shift from the withdrawal of legal capacity to the right to support for exercising legal capacity.

3.1 Understanding disability in the human rights context

This paradigm shift permeates the notion of disability in the human rights context. The CRPD affirms that disability is a consequence of the interaction between persons with impairments and the environment. It is only when the environment fails to accommodate the needs of the individual that disability occurs.²² For example, if a citizen with Down's syndrome who considers applying for a certain service is provided information in easy-to-read format and adequate support and time to consider her options, she may be able to understand what the service is about and to choose whether or not to use it. In such a situation no disability arises. However, if information is only provided in standard (and to the individual inaccessible) language and no one offers to explain it to the individual in a manner that he or she understands, disability becomes a fact. This way of understanding disability is fundamentally different from viewing disability as a consequence of the individual's impairment. It means that it is the society's failure to create an inclusive environment that disables individuals rather than any mental or intellectual conditions attached to the person.

By placing the 'problem' of disability in the (inaccessible) environment, the solution is to be found there as well. The shift calls for legal, attitudinal and environmental changes. Existing barriers preventing persons with disabilities from being in control of their lives on an equal basis with others needs to be removed, and new systems should be developed enabling persons with disabilities to make choices, live in the community and participate in society. The European Action Plan describes it as follows:

"[We] have moved from seeing the disabled person as a patient in need of care who does not contribute to society to seeing him/her as a person who needs the present barriers removed in order to take a rightful place as a fully participative member of society. Such barriers include attitudes and social, legal and environmental barriers. We therefore need to further facilitate the paradigm shift from the old medical model of disability to the social and human rights based model.

*We have shifted our focus to the individual as central to a coherent, integrated approach which respects the human rights, fundamental freedoms and dignity of all disabled individuals. Consequently there has been a shift in many European countries to promote active policies which empower the individual disabled person to control his/her life [...]."*²³

Being members of and participants in a society are both crucial aspects of personhood and legal capacity. It is this belonging to and interaction with our family, friends and fellow citizens that enable us to make choices and empower us to be in control of our lives. The link between community living and recognition of legal capacity is therefore obvious. Not only do you need legal capacity to decide where and with whom to live. In fact, humans are only able to develop

²² CRPD article 1 and preamble para e).

²³ Recommendation Rec(2006)5 of the Committee of Ministers to Member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, referred to as the Council of Europe Disability Action Plan 2006-2015, para 2.2.

their capacities to take decisions and make choices when embedded in a social context. None of us is born with such capacities; making decisions is something we learn from parents, friends, teachers and others.

3.2 Equality in the disability context

The CRPD was developed on the basis of the recognition that the existing human rights framework had failed to protect the human rights of people with disabilities in an equal measure with others. Hence, the principle of equality underpins the entire convention. It is not about creating 'separate' or 'special' rights for persons with disabilities, but about including persons with disabilities in the existing human rights discourse and tailoring existing rights to fit their needs. While the CRPD concerns primarily the situation of persons with disabilities, it also addresses the general human rights discourse. It presents a fully developed concept of equality in human rights terms. It moves beyond formal equality and creates an understanding of equality that is closely linked with the perception that disability is a disadvantage that occurs when persons with impairments meet an inaccessible environment and not a characteristic simply imputable to the individual.

This understanding of equality has shaped the definition of discrimination, which is defined as follows in the Convention:

"[any] distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation" (Article 2 of CRPD)

By including all acts that have the *purpose or effect* of impairing or nullifying human rights, the definition prohibits both direct and indirect discrimination. In addition, and this is of crucial importance for the effective prevention of disability-based discrimination, states are obliged to provide reasonable accommodation (Article 5.3 of CRPD). Reasonable accommodation is defined as the "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms" (Article 2 of CRPD).

This means that, in order not to discriminate, employers, schools, local authorities, transport companies and all others that offer services to the general public, must take action to ensure that their services are accessible also for persons with disabilities. The restaurant owner may put up a ramp for his customers in a wheelchair, or offer to read the menu to those with visual impairments. The employer may offer flexible working hours or a quiet working area for those with psychosocial disabilities who need it to be able to work effectively.

We may already be used to thinking about reasonable accommodation in terms of ramps and work place adjustments, but the concept also applies to the decision-making process where individuals interact with each other. Echoing the example described above, persons with intellectual or psychosocial disabilities may not, at the outset, understand the implications of certain transactions and interventions such as taking a loan, terminating an insurance policy or consenting to or refusing a medical operation. In such cases, the bank, insurance company and doctor have an obligation to take positive measures (to the limit of disproportionate or undue burden) to accommodate the individual, to ensure that he/she is put in an equivalent position with others.

Adjustments of this kind could involve the review and simplification of customer procedures related to contractual agreements. Information could be provided in easy-to-read or other alternative formats. The doctor could spend additional time in explaining the proposed medical procedure, its risks and possible benefits, as well as give the individual some more time to think it through. It could even be as simple as accepting that some customers are assisted by family and

friends when communicating their decisions and choices. Both public authorities and private enterprises are covered by the duty of reasonable accommodation (Article 4d and e of the CRPD).

The prohibition of discrimination contained in the European Convention of Human Rights (European Convention) also goes beyond simply treating equals in an identical manner. In *Thlimmenos v. Greece* the Court held that the convention is not only violated when States treat persons differently in analogous situations without providing an objective and reasonable justification, but also “when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different”.²⁴ The Court has further recognised that states have an obligation to accommodate the needs of persons with disabilities in state institutions, such as prisons.²⁵

In *Glor v. Switzerland*²⁶ these arguments were applied to a complaint of disability-based discrimination. The case concerned a man who was prepared to carry out his military service but deemed medically unfit to do so due to his diabetes. Alternative civilian service was only available for conscientious objectors. Due to not having performed national service, Glor had to pay a military service exemption tax on his annual earnings. Persons with more complex disabilities, who were not able to complete military duty, were exempted from the tax. But not Glor. The diabetes was not considered severe enough to relieve him from the tax.

The Court reiterated that the list of grounds of discrimination set out in Article 14 was not exhaustive and that it without doubt also prohibited discrimination based on a disability. The Court continued to state that not all differences in treatment would constitute discrimination. Only in cases where the individual was disadvantaged compared to others similarly situated and where the difference in treatment lacked objective and reasonable justification was discrimination prohibited. Glor was treated differently than persons with more complex disabilities as well as conscientious objectors, which both could escape the tax without performing military service. According to the Court, this difference in treatment was neither objective nor reasonable and that Switzerland had failed to provide alternatives for persons with (less severe) disabilities. This obligation to provide alternatives, to adjust the system so that persons with disabilities have equal options, is very similar to the CRPD’s notion of reasonable accommodation.

4. Human rights standards on legal capacity

The paradigm shift and the principle of equality as described above call for a new approach to legal capacity. The paradigm shift urges us to change the environment instead of trying to ‘fix’ individuals. The demand for equality compels us to develop alternatives to accommodate and enable all persons with disabilities to be in charge of their lives. The human rights standards outlined below provide further advice on how this should be put into practice.

²⁴ *Thlimmenos v. Greece*, Application no. 34369/97, 6 April 2000. The case concerned a man who was refused an appointment as a chartered accountant on the basis of a previous criminal conviction, which comprised of disobeying, due to his religious beliefs as a Jehovah’s Witness, an order to wear military uniform. National legislation excluded all persons convicted of a crime applied from civil service posts. The applicant’s refusal to wear a military uniform stemmed from religious convictions and could not imply that he was morally or mentally unfit to join the chartered accountancy profession. Hence, the state had no objective and reasonable justification for excluding him from being an accountant.

²⁵ *Price v. The United Kingdom*, Application no. 33394/96, 10 July 2001. The case concerned a woman in a wheelchair put in a prison not accommodated to her needs. She was complaining of the cold every half hour - a serious problem for the applicant who suffered from recurring kidney problems and who, because of her disability, could not move around to keep warm. In addition, she could not use the bed and had to sleep in her wheelchair. She got a space blanket and painkillers from the prison doctor, but no other action was taken. The Court found that the failure to provide appropriate provisions amounted to degrading treatment under Article 3 (prohibition of torture). Though not explicitly a discrimination-case, Judge Greve found the treatment, in her separate opinion and with reference to *Thlimmenos*, amounted to discrimination.

²⁶ *Glor v. Switzerland*, Application no. 13444/04, 30 April 2009.

4.1 The Convention on the Rights of Persons with Disabilities: equality before the law

Article 12 of the CRPD is entitled “equal recognition before the law” and considered to be the beating heart of the convention. It is closely related to social inclusion, autonomy and equality, all core values of the instrument, and reads as follows:

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.*

It is clear that full/equal legal capacity for everyone is the CRPD’s point of departure (Article 12.1-2). States Parties cannot continue to deny legal capacity from people with disabilities or impairments. It is equally clear that the primary response to situations where someone is considered to have difficulties in making decisions and/or communicating them to others should be to provide support (Article 12.3). The CRPD approach to personhood and legal capacity is therefore inherently different from the guardianship practices in many Council of Europe member states where persons with intellectual and/or psychosocial disabilities, instead of being empowered to formulate their choices, are deprived of their capacity and given a guardian to take decisions on their behalf.²⁷

The obligation to provide access to support (Article 12.3) and the duty to reasonably accommodate described above (Article 5.3) complement each other. They rest on the same idea, i.e. that current systems and procedures for exercising legal capacity are not designed to be accessible to persons with disabilities and hence need to be adjusted to comply with the principle of equality. But whereas Article 5.3 is silent on the types of accommodation that need to be made, Article 12.3 contains an explicit obligation to ensure *access to support*. The wording “access to support” further implies that support is to be provided on a voluntary basis and that the state does not have to be the actual provider of such support. The state obligation is to see to it that support is available, regardless of whether the support is actually carried out by public entities, civil society, family and friends or a mixture of public and private parties.

The supports that Article 12 calls for can take a variety of forms including support to enable someone who communicates in alternative ways to convey his/her message to third persons;

²⁷ See e.g. Office of the High Commissioner for Human Rights ‘Monitoring the Convention on the Rights of Persons with Disabilities - Guidance for human rights monitors’, Professional training series No. 17, p. 26 which states: “*The right to equal recognition before the law requires, inter alia, eliminating disability as a ground for depriving someone of his or her legal capacity—for example, by eliminating the practice of appointing guardians who make decisions on behalf of persons with disabilities and, instead, providing support to persons with disabilities so that they can make their own decisions.*”

support to assist someone in their contacts with the authorities; and life planning supports to assist a person in thinking about options for living and other arrangements. Common to all these measures is that the choices rest with the individual. Third parties, i.e. public officials, doctors, social workers, bank employees and others must in turn take measures to enable the individual to enter into agreements and make other decisions with legal consequences (reasonable accommodation).²⁸

Article 12.4 concerns safeguards. At the first glance it may look like a fossil from the old paradigm, where substituted decision-making was the main rule. However, safeguards will be necessary in the new paradigm as well. Replacing guardianship with support systems will transfer power back to the individual, but it does not eliminate all risks of manipulation and abuse.

There may still be persons whose decisions and choices we cannot understand today, despite efforts to support the individual coupled with adjustment efforts from third parties. In such cases we may have to resort to 'best interests' reasoning trying our best to find out what the person would have wanted, if we had been able to understand him or her. However, this does not mean that states can continue to deprive this group of their legal capacity. Instead, we need to develop different types of support, in dialogue with users, so that over time we will get better at understanding the choices and preferences of our fellow citizens.²⁹ The importance of developing community living alternatives re-connecting persons' social networks cannot be overestimated in this context. It is in relation with others that we shape our personalities and preferences. All of us need social capital to make choices about our lives.

4.2 The European Convention on Human Rights

4.2.1 The (un)lawfulness of deprivation of legal capacity

Although the European Convention on Human Rights does not directly refer to legal capacity, depriving individuals of their legal capacity constitutes a serious interference with the individual's right to respect for private life (Article 8).³⁰ Drawing on its case law concerning deprivation of liberty, the European Court of Human Rights has established that the existence of a mental disorder, even a serious one, cannot be the sole reason to justify incapacitation. Only mental disorders of a certain "kind or degree" can justify incapacitation.

The applicant in *Shtukaturov v. Russia* was diagnosed with schizophrenia and considered violent, "anti-social" and unable to understand his actions according to a medical report. However, because the report did not specify which actions he was unable to understand, incapacitation was found contrary to Article 8. With reference to the principles formulated in the Committee of Ministers Recommendation No. R (99) 4³¹, the Court criticised the state for not providing tailor-made responses to persons in need of assistance, and concluded that, as a result, the applicant's rights under Article 8 had been limited more than strictly necessary.³² This principle of proportionality and necessity was confirmed in *Salontaji-Drobnjak v. Serbia* where the Court concluded that also legal capacity restrictions, which are in accordance with domestic law and have a legitimate aim, need to be proportionate to comply with the European Convention. Full incapacitation does not meet this criterion.³³

In the recent case of *Stanev v. Bulgaria*, the Court had the opportunity to elaborate its position on more limited incapacitation and legal representation arrangements. The case concerned a man put under partial guardianship: he was able to undertake ordinary acts of everyday life and had access to some of his resources. However, the applicant was prevented from performing a

²⁸ Bach and Kerzner, pp. 101-102.

²⁹ Gerhard Quinn, ['Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD'](#), HPOD Conference, Harvard Law School, 20 February, 2010.

³⁰ *Shtukaturov v. Russia*, Application no. 44009/05, para 90; and *Salontaji-Drobnjak v. Serbia*, Application no. 36500/05, para 144.

³¹ Recommendation No. R (99) 4 by the Committee of Ministers on principles concerning legal protection of incapable adults, 23 February 1999. The title is unfortunate and signals an outdated view on persons with disabilities, but the principles are still relevant.

³² *Shtukaturov v. Russia*, para 90, 93-95.

³³ *Salontaji-Drobnjak v. Serbia*, 13 October 2009, para 144.

number of legal transactions and was not able to access courts to challenge his incapacitation and the following detention in a social care home. He contended that the guardianship under which he had been placed was not geared towards his individual needs but entailed a number of restrictions automatically imposed on everyone under that regime. This, in combination with the obligation to live in a social care home, had effectively deprived him of participating in community life and developing personal relationships.³⁴

In its Grand Chamber judgment on *Stanev v. Bulgaria*, the Court stressed the growing importance international law, including the CRPD, now attaches to granting persons with psychosocial disabilities as much legal autonomy as possible. In addition to concluding that the conditions at the social care home had amounted to degrading treatment and a violation of Article 3, the Court found that the deprivation of liberty of the applicant had been unlawful and that his lack of access to court to challenge the lawfulness of his detention and to seek restoration of his legal capacity had breached Articles 5 and 6 of the Convention. However, the Court considered that no separate issue arose under Article 8.³⁵

Since the Court continues to recognise mental disorder as a possible justification for limiting legal capacity, the European human rights system has not yet fully incorporated the paradigm shift envisioned in the CRPD towards granting persons with disabilities a primary right to support in their decision-making. The Parliamentary Assembly Resolution 1642 (2009) referred to in the introduction nevertheless points in the direction of this paradigm shift. It invites member states to guarantee that people with disabilities retain and exercise legal capacity on an equal basis with other members of society by “ensuring that their right to make decisions is not limited or substituted by others, that measures concerning them are individually tailored to their needs and that they may be supported in their decision making by a support person” (para. 7.1). It continues to state that where support is needed, it should be afforded to persons with disabilities without their wishes or intentions being superseded (para. 7.2).

4.2.2 Fair procedures

Court proceedings concerning legal capacity relate to a person’s civil rights and must therefore comply with the fair trial guarantees of Article 6.1 of the European Convention. States Parties have a certain margin of appreciation to determine the procedural arrangements to ensure fair trial, but the minimum guarantees of Article 6 must be complied with.³⁶ This means that the individual concerned has the right to participate in proceedings concerning his/her legal capacity. Given the individual’s dual role – as an interested party and, at the same time, the main object of the court’s examination – his/her participation is necessary “not only to enable him to present his own case, but also to allow the judge to form a personal opinion about the applicant’s mental capacity”.³⁷

States Parties should also ensure that the individual concerned enjoys equality of arms with the party making the application. Whilst the Convention does not guarantee free legal aid in all cases concerning civil rights, Article 6 obliges States Parties to provide such assistance if it proves indispensable for effective access to court. Whether such an obligation exists is determined by the complexity of the case and the procedures involved, the importance of what is at stake and the financial situation of the individual.³⁸ Most legal capacity proceedings today involve both expert evidence (usually medical reports) and a court hearing rendering the proceedings rather complex. The stakes for the individual are obviously high. For this reason the Court has considered them to be on par with deprivation of liberty.³⁹

³⁴ *Stanev v. Bulgaria*, Application no. 36760/06, 17 January 2012.

³⁵ *Stanev v. Bulgaria*, paras 244 and 250-252.

³⁶ *Matter v. Slovakia*, Application no. 31534/96, 5 July 1999, para 51.

³⁷ *Shtukaturov v. Russia*, para 72 and *Salontaji-Drobnjak v. Serbia*, para 127. See also *X. v. Croatia*, where a parent was automatically excluded from participation in proceedings concerning the adoption of her child, which was considered a violation of article 8.

³⁸ *Airey v. Ireland*, para 26; *Steel and Morris v. UK*, Application no. 68416/01, 15 February 2005, para 62-65; and *Megyeri v. Germany*, Application no. 13770/88, 12 May 1992, para 23.

³⁹ *Shtukaturov v. Russia*, para 71. This statement recognises the necessity of fair trial guarantees as laid down in article 6 in legal capacity procedures.

Fair procedures will not replace or legitimise unfair systems of guardianship that need to be replaced. However, while such systems are still in place, fair trial guarantees must be observed. New support systems, when they involve court procedures, will also need to meet the standards of fair procedures.

4.2.3 Appeal and review

The Court has found violations in systems where persons under guardianship cannot challenge the incapacitation themselves because of the very fact that they are under guardianship. In *Shtukurov v. Russia*, the guardianship could only be challenged by the guardian who opposed its discontinuation. This together with other procedural flaws led the Court to conclude that the applicant's participation in the decision-making process had been "reduced to zero", and was thus in violation of Articles 6 and 8.⁴⁰ In *Salontaji-Drobnjak v. Serbia* an appeal could not effectively be brought before a court even with the assistance of the guardian. This together with the lack of periodical review of the continued need for guardianship led the Court to conclude that the applicant's right to access justice had been impaired in violation of Article 6.⁴¹ As regards persons placed under partial guardianship it is clear that direct access to review procedures must be ensured.⁴²

States retain a "margin of appreciation" as to the facilitation of access to appeal and review procedures in the national context. According to the Court, some restrictions on a person's procedural rights may be justified for the person's own protection, the interest of others and the proper administration of justice. However, the least restrictive means should be used. Problems related to excessively frequent applications should not be solved by the denial of access altogether. Instead, the number of complaints within certain time frames could be limited.⁴³ The application of a period of three years within which no application for restoration of legal capacity can be made has nevertheless been deemed too restrictive by the Court.⁴⁴ In sum, this means that also persons under guardianship regimes must retain legal capacity to apply for restoration of their full legal capacity within a reasonable period of time.

4.2.4 Enjoyment of other rights

The Court has on several occasions acknowledged the importance of legal capacity to exercising one's human rights. It has found violations of the rights of persons whose legal capacity has been removed with respect to a number of rights, including the right to liberty, the right to property, the right to vote and the right for parents to participate in child adoption proceedings. The Court has rejected the practice of "voluntary" hospitalisation against the individuals' will but with the consent of his/her guardian. Incarceration against the individual's will is deprivation of liberty and needs to comply with the safeguards laid down in Article 5.⁴⁵ The same applies to placements in social care homes without the consent of the individuals concerned in cases where their de facto possibilities for leaving the institution are significantly restricted.⁴⁶

In *X v. Croatia* the Court ruled out an automatic exclusion of incapacitated persons from adoption proceedings concerning their children. Parents deprived of legal capacity should also have the opportunity to be heard in such proceedings and be able to express their views about the potential adoption.⁴⁷ *Zehentner v. Austria* concerned a woman whose apartment was sold in her absence following a request from her creditors. The woman had a nervous breakdown, ended up in a psychiatric hospital and was subsequently placed under guardianship. She unsuccessfully tried to annul the sale of her home. The Court concluded that the procedural mechanism did not

⁴⁰ *Shtukurov v. Russia*, paras 90-91.

⁴¹ *Salontaji-Drobnjak v. Serbia*, paras 134-135.

⁴² *Stanev v. Bulgaria*, para 241.

⁴³ *Stanev v. Bulgaria*, para 242.

⁴⁴ *Berková v. Slovakia*, Application no. 67149/01, 24 June 2009, para 175. In this case the three-year period was motivated by the argument that it could not be expected that the individual's health would improve. Considering the serious interference such a restriction meant for the applicant's private life, it was deemed contrary to Article 8.

⁴⁵ *Shtukurov v. Russia*.

⁴⁶ *Stanev v. Bulgaria*, paras 121-132.

⁴⁷ *X v. Croatia*, Application No. 11223/04, 17 July 2008, para 53.

offer adequate protection to a person lacking legal capacity. Due to her lack of legal capacity, she had been unable to object to the payment order related to the sale of her apartment and to make use of other remedies available to debtors. Article 1 of Protocol No. 1 had been violated.⁴⁸

The Court has also rejected automatic disenfranchisement of persons placed under guardianship. Applying a functional approach to legal capacity the Court has accepted that the right to political participation could be limited for persons who did not understand the consequences of their decisions. The routine removal of voting rights of persons under guardianship, irrespective of their actual faculties, was however deemed in violation of Article 3 of Protocol No. 1.⁴⁹

This illustrates the central role legal capacity plays in the protection of human rights. Without it, most other rights are brutally circumscribed. This is why Article 12 is considered a core provision of the CRPD and it is one of the reasons why the Court considers full incapacitation a violation of Article 8 of the European Convention.⁵⁰

4.2.5 Provision of support

The need to develop tailor-made measures to persons in need of assistance has been highlighted in the Court's case law with reference to the Committee of Ministers Recommendation No. R (99) 4.⁵¹ This Recommendation builds on the functional approach to legal capacity, linking recognition of legal capacity to cognitive skills to understand the nature and consequences of a certain decision. As such, it is not fully compatible with article 12 of the CRPD. Nevertheless, the Court has considered the Recommendation to express "a common European standard" in this area.⁵² When read in the light of the CRPD, several of the Recommendation's guiding principles could be informative for the process of developing the support that should replace current guardianship mechanisms.

In the process of developing adequate support to enable persons with disabilities to exercise their legal capacity, it is important to identify the challenges experienced by this group. Persons experiencing difficulties in understanding information and/or reaching a decision should receive assistance, without running the risk that the support given would take over the entire decision-making process. Similarly, those persons who only face problems in communicating their will to third parties should have access to that type of support, without having to defend their decision to the support person. If applied in this way, the functional approach still has a role to play as a model for designing appropriate support so that the individual can be put on an equal footing with others.

The Recommendation views decision-making capacities to be time and situation specific based on an understanding that a person's capacities may change over time and are relative to the decision to be made. A person's (in)capacity to make decisions about how to administer one's financial assets is not necessarily relevant to the person's capacities to choose where to live or decide on medical treatment and vice versa. The second principle of the Recommendation, for example, calls for flexibility in the legislative framework to ensure suitable measures sensitive to different degrees of capacity and to the different situations warranting support. This moves beyond just giving preference to the 'least restrictive alternative' and requires states to develop truly suitable measures to meet the needs of those who want support, including support that *does not* restrict the legal capacity of the person concerned. Its corollary, the principle of maximum preservation of capacity, means that no measure should result in the automatic or complete removal of the legal capacity of the person concerned. Principle 5 states that support should only be provided if necessary or with the consent of the individual. The explanatory memorandum further mentions the support functions carried out by family and friends. It acknowledges that this

⁴⁸ *Zehentner v. Austria*, Application no. 20082/02, 16 July 2009.

⁴⁹ *Alajos Kiss v. Hungary*, Application no. 38832/06, 20 May 2010.

⁵⁰ *Shtukaturov v. Russia*, para 90.

⁵¹ *Shtukaturov v. Russia*, para 95.

⁵² *Shtukaturov v. Russia*, paras 59 and 95; and *Salontaji-Drobnjak v. Serbia*, para 107. Compliance with the Recommendation from 1999 will not be enough to bring about the paradigm shift envisaged in article 12 of the CRPD. But breaching the principles outlined below will most certainly also violate the human rights standards laid down in CRPD.

group of supporters often operates in a legal vacuum and encourages states to legally recognise this type of support and provide appropriate safeguards.⁵³ If developed properly, this would be an embryo of what in Canada are called “support networks” (see further chapter 5).

Interpreted in this manner, the functional approach no longer focuses on the capacities of the individual alone, but on the capacity of the decision-making process when appropriate support and reasonable accommodation are provided. This is not only more empowering and useful for the individual concerned, it would also bring the principles laid down in the Recommendation much closer to the understanding of personhood and legal capacity manifested in the CRPD.

5. The way forward

European legal concepts on personhood have tended in the past to build on the idea of a ‘rational and reasonable person’ – an individual who rationally processes information, chooses between foreseeable alternatives based on an analysis of their consequences and then arrives at a rational outcome, an informed decision.⁵⁴ The problem with this idea is not only that it can exclude persons with certain disabilities but that it is based on false premises. Decision-making is a complex process which occupies researchers and scholars worldwide. The choices and decisions we make are seldom purely rational. To process all possible alternatives in any given situation is rarely possible or desirable considering the amount of time it would require. Our emotions affect our decisions as to what options are worth thinking about and which are not. The process is further influenced by our experiences and social and cultural backgrounds, including our personal networks. We also take risks and make mistakes. Some mistakes we learn from, others we repeat.

The model of personhood and legal capacity embedded in article 12 of CRPD is much more inclusive than the idea of the ‘rational person’. It recognises the reality behind all persons’ decision-making and emphasises support instead of stripping persons of their legal capacity to make choices. As pointed out by Michael Bach, the question is no longer: does a person have the mental capacity to exercise his/her legal capacity? The question is instead: what types of support are required for the person to exercise his or her legal capacity? This is a profound shift in the law of legal capacity.⁵⁵

5.1 Reform of existing systems

Several steps need to be taken to bring European systems relating to legal capacity in line with the European Convention and the CRPD. Firstly, mechanisms providing for full incapacitation and plenary guardianship must be abolished and the assumption of legal capacity extended to persons with disabilities. Having an intellectual and/or psychosocial disability cannot be a reason for not benefitting from the presumption of capacity. Secondly, we need to review and reform discriminatory legislation depriving persons with disabilities of other human rights (such as their rights to a fair trial, to vote and to property) for reasons linked to disability or impairment.

Thirdly, governmental and local authorities, courts, health care and other service providers have to make their services more accessible to persons with disabilities. Reasonable accommodation to persons with disabilities trying to access their services is the minimum. This includes the provision of information in plain language and the acceptance of a support person communicating the will of the individual concerned.

5.2 Development of adequate support

As with all disability policy and reform, a twin-track approach needs to be adopted which works towards making general procedures for legal transactions more accessible while, at the same time, developing more individualised tailor-made support measures for those who want such

⁵³ Explanatory Memorandum, Recommendation No. R (99) 4 by the Committee of Ministers on principles concerning legal protection of incapable adults, 23 February 1999, para 34.

⁵⁴ Gerard Quinn, ‘Article 12 of the UN Convention on the Rights of Persons with Disabilities: Is there a Third Way?’ presentation delivered at a research conference in Reykjavik, Iceland, 28 May 2011.

⁵⁵ Bach and Kerzner, p. 58.

assistance to exercise their legal capacity. At the national level, support measures will have to fit with the legal system to become effective. Their design will therefore depend on individual needs as well as the type of challenges persons with disabilities face when trying to exercise their legal capacity in a given national context. As individuals will need and want different types of support, member states should strive towards developing a range of different support options rather than trying to find one model for all. Persons with mental and/or intellectual disabilities are just as heterogeneous decision-makers as the rest of us. Some will prefer powers of attorney or advanced directives, others will need communication support and yet others will want someone with whom to discuss complex options and decisions. A good way to start the procedure and gain information about what type of support persons with disabilities want in the national context is to initiate a dialogue with civil society organisations.

There will be challenges with this new approach to legal capacity as well. One of them is to ensure that our new systems are truly support systems and not substituted decision-making under a new name. Appropriate safeguards should be put in place to ensure that support persons act diligently and in good faith, respecting the autonomy and dignity of their clients. Another challenge lies in the fact that reforming legal capacity systems is path-breaking work. There are examples of good practices, but no country has yet gone all the way and fully implemented the paradigm shift of article 12 of the CRPD. The potential benefits, first and foremost for those currently trapped in paternalistic guardianship systems, should far outweigh any reticences to embarking on a reform course.

Two examples of decision-making support in line with article 12 of the CRPD where the individual retains his/her full legal capacity are described below. Personal ombudsmen were primarily developed to suit persons with psychosocial disabilities while support networks originated from within the disability movement of persons with intellectual disabilities. Both systems are the result of close co-operation between the state and the disability movement.

5.2.1 The example of personal ombudsmen

The personal ombudsmen support model in Sweden was developed based on a recognition that existing legal capacity systems did not meet the needs of many people with psychosocial disabilities who were pushed between authorities and unable to access their rights. It started as a pilot project, but showed such good results – it was appreciated by the clients, it reduced the number of in-patient hospitalisations and resulted in cost-savings – that today it has become a country-wide permanent arrangement of about 300 ombudsmen supporting 6000-7000 persons with psychosocial disabilities.⁵⁶

The ombudsman is a professional who works 100 % on the commission of the individual, and for the individual only. The ombudsman has no commitments or responsibilities vis-à-vis the medical or social services or any other authority or person. The ombudsman only acts when the client wants him/her to do so. It may take long a time before the ombudsman and the individual have developed a trustful relationship where the individual wants to talk about what kind of support he/she wants, but the ombudsman needs to wait, even if the client's life may appear chaotic. This type of support has been successful in helping also those who are most hard to reach and who have previously often been left without support. This includes persons diagnosed with schizophrenia, persons experiencing delusions and psychosis, and those who are homeless or live very isolated avoiding all contact with the authorities. To reach this group, the ombudsman has to actively seek contact on the individual's terms. A number of characteristics have contributed to the success of the personal ombudsman model. These include:

- No bureaucratic procedure to get a personal ombudsman. Requirements to fill in forms would prevent many who need the ombudsman, to get one. A simple yes to the question from an ombudsman to the client if he/she wants an ombudsman is enough.

⁵⁶ The Swedish National Board of Health and Welfare, *Egen kraft – egen makt, En antologi om arbetet som personligt ombud* [Your own strength – your own power, An anthology about the work of personal ombudsmen], p. 15.

- The ombudsman does not work ordinary office hours but holds flexible hours and is prepared to have contact with his/her clients also in the evenings or on weekends.
- The ombudsman is comfortable to support the client in a number of matters. The priorities of the individual are not always the same as the priorities of the authorities or the relatives. The client's first priorities may not concern housing or occupation but relationships or existential matters. An ombudsman must be able to discuss such matters as well - and not just 'fix' things.⁵⁷

5.2.2 *The example of support networks*

The British Columbia's (Canada) Representation Agreement Act is another example of good practice, in particular appreciated by organisations representing persons with intellectual disabilities.⁵⁸ The purpose of the Act is to establish a mechanism allowing adults to arrange in advance how decisions should be made if they were to become in a situation where national law does not recognise their capacity to make legally valid decisions without support. The Act provides for the individual to draw up representation agreements where he/she authorises another person, freely selected by the individual, to support the individual or to make decisions on behalf of the individual in selected areas of life. This may include routine financial managements, health care choices or obtaining legal services for the adult.⁵⁹

Such types of support mechanism are progressive in that they leave it to the individual to choose his/her support and the areas in which he/she wants support. The act is also noteworthy because it extends the presumption of capability also to persons with intellectual and/or psychosocial disabilities. Also adults who would not be considered capable of managing their financial affairs under ordinary contract law are allowed to make representation agreements (as well as change and revoke them). When deciding whether an adult can make such an agreement, the 'understand and appreciate test'⁶⁰ does not apply. Instead, consideration is given to whether the adult can communicate a desire to get help, can express preferences, is aware of the fact that concluding the representation agreement means that the representative may make decisions or choices that affect the adult, and whether the adult has a relationship with the representative that is characterised by trust.⁶¹

⁵⁷ Maths Jespersson 'Personal Ombudsman in Skåne – A User-controlled Service with Personal Agents' in P. Stastny and P. Lehmann (Eds.), *Alternatives Beyond Psychiatry*, 2007, p. 299ff.

⁵⁸ Representation Agreement Act, R.S.B.C. 1996, chapter 405.

⁵⁹ Representation Agreement Act, para 7.

⁶⁰ I.e. that a person can understand the nature of a decision and appreciate the reasonably foreseeable consequences.

⁶¹ Representation Agreement Act, para 8. For further reading, see Bach and Kerzner.

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